

## **DOCTORAL THESIS**

### **Building bridges of understanding**

### **The use of embodied practices with older people with dementia and their care staff as mediated by dance movement psychotherapy**

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*Award date:*  
2009

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**‘BUILDING BRIDGES OF UNDERSTANDING:  
THE USE OF EMBODIED PRACTICES WITH OLDER PEOPLE WITH  
DEMENTIA AND THEIR CARE STAFF AS MEDIATED BY DANCE  
MOVEMENT PSYCHOTHERAPY’**

**by**

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**A thesis submitted in partial fulfilment of the requirements for the degree of**

**PhD**

**School of Human and Life Sciences**

**Roehampton University**

**University of Surrey**

**2009**

This thesis is dedicated to the life and work of Bani Shorter, AB, MA, Dipl Analyst  
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## **Abstract**

This study investigates the use of Dance Movement Psychotherapy (DMP) on people with dementia, on care-staff, on embodied practices and the author's own reflections and developing understanding about their use and importance. Embodied practices mean engaging with a person through the lived experience of their own body in relationship to self and others, thus people with dementia can be more effectively reached and communicated with. Embodied practices contributed to: improving mobility; affirming identity; supporting affective communication; increasing observed 'well-being' and extending the range and quality of care relationships.

This study proposes care-staff need to be better informed psychologically about how to engage, how to 'build bridges of understanding' between the 'known' and the 'not yet known'. Care-staff need to be more accepting that communications and behaviours expressed through 'strangeness' and 'otherness' can be better understood and related to as having meaning and importance. This is a paradigm shift away from bio-medical thinking, placing the onus on care-staff becoming more adept at communicating and finding meaning in so-called 'non-sense'. Embodied practices support remaining individual capacities and communication skills and by way of this, 'Personhood' (Kitwood and Bredin, 1992a: 274).

The fieldwork was within a mental-health hospital ward in England. A single DMP session was studied using a qualitative and quantitative methodology, regarding impact on the patient, on care-staff, and on the use of embodied practices. It was recorded on video (VTR), mapped using Dementia Care Mapping (DCM) with the impact on care-staff studied using questionnaires. Analysis of the VTR transcript yielded thirty-three linked themes leading to five further meta-themes. DCM results indicated significant effects on raising and supporting observed 'well-being', consistent with other sessions of a similar type (Crichton, 1997, Perrin, 1998).

Contribution to knowledge concerns the development of a more creative, more expressive and embodied approach to the care of people living with dementia as presented here by the development of a new approach called 'Creative Care'.

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## ACKNOWLEDGEMENTS

This acknowledges the people with whom I have discussed ideas, who have participated in the embodied practices or who have supported me in making it happen in any number of ways. I am indebted to them all for helping me open my thinking, my feeling, my intuiting and of course my ‘moving’ towards that which has coalesced here and for their support however large or small. I am also grateful to my current employer for their financial support, the South West Yorkshire Partnership Foundation NHS Trust.

Mrs Mary & Miss Amy Coaten Dr Janek Dubowski Professor Jen Coates  
Professor Andree Grau Dr Galfrid Congreve Dr Michael Barham Mrs Penny Best  
The late Mrs Gabrielle Parker Dr Patrick MacManaway Dr Kim Jobst  
Dr Roger Greenaway Dr Amanda Ravetz Dr Alison Phinney Mr John Killick  
Mrs Bani Shorter Professor Dawn Brooker Mrs Sarah Holden Dr Heather Hill  
Dr Pia Kontos Mrs Jo Crossland Professor Caroline Cantley Dr Robert Orange  
Ms Melanie Riley Mr Charles Whitehead Assoc. Prof. Emerita J Evetts-Secker  
Mrs Susan Scarth Dr Bonnie Meekums Mrs Sue Benson Ms Catherine Beuzeboc  
Ms Nina Papadopoulos Dr Andrew Samuels Ms Fiona Hoo Dr Nisreen Booya  
Mr David Sheard Mr Alan Chapman Dr Errollyn Bruce Professor Murna Downs  
Dr Richard Ward Professor Mary Marshall Ms Kate Allan Mr Alan Batson  
Ms Katy Dymoke Dr Harriet Mowat Ms Sarah McCormack Mrs Kath Mashinter  
The late Mrs E Blaymires Professor Malcolm Johnson Professor Alistair Burns  
Ms Miranda Tufnell Mr Anthony Rumgay Mrs Susan Scarth Dr Laurel Spooner  
Dr Jane Clark Mrs Christine Jackson Mrs Jenny Carey Mrs Maggie Bell



# Chapter 1

## Introduction

In Korsakov's, or dementia, or other such catastrophes, however great the organic damage and Humean dissolution, there remains the undiminished possibility of reintegration by art, by communion, by touching the human spirit: and this can be preserved in what seems at first a hopeless state of neurological devastation (Sacks, 1985: 37/38).

These words, written in 1985, remain important today for all those who attempt, as I do now in this thesis, to explore in detail the territory so movingly described here by Sacks. The territory is difficult to define, to get under the skin of, yet it represents a profoundly important attempt metaphorically speaking, to say 'yes' to 'the undiminished possibility' *of that which remains*, and 'no' to acceptance of hopelessness and helplessness in spite of severe 'neurological devastation'. It does not belittle the power of neurological insult to do great damage to human life, it does represent a call from a highly skilled, respected and experienced neurologist to look to the power of art to help 're-integrate'; or in the study described here for the power of Dance Movement Psychotherapy (DMP) to make a real contribution to improving the quality of life for people with the condition and those caring for them. These words were written in the same year I began my movement and dance work with people living with dementia and their care-staff and will be the only ones used to frame a chapter in this way.

This study is seeking to better understand the lived experience of older people with dementia and their care-staff in the care environment, including the use and importance of ‘embodied practices’ and DMP in particular. It comes at a time in the United Kingdom, and internationally, when there is an urgent need for this understanding. Current economic, societal, familial, personal and psychological costs impact greatly on all those directly involved, with numbers of people affected and costs to the State projected to increase very substantially in the coming years (see Chapter 3 section 3.2). The different problems, challenges and ethical issues presented in this thesis in relation to work in this important area of the care sector are counter-balanced by what is at the heart of the argument presented here: namely that people in spite of severe cognitive impairment *can be reached by way of the body*, and by what I have described here as the use of ‘embodied practices’. Embodied practices used here and throughout the thesis mean paying attention to, and engaging with a person, through the lived experience of their own body in relationship to self, others, and being *in* the world. Merleau-Ponty (1962) has described this as “tacit knowledge”, which Kontos (2005) has taken further and specifically into the contemporary dementia care context calling it “embodied selfhood”. She argues powerfully that, ‘...dementia care practices must embrace the idea that the body is a fundamental source of selfhood that does not derive its agency from a cognitive form of knowledge’ (op.cit.: 553). I agree wholeheartedly with this argument. While aiming to better understand the lived experience of older people with dementia and those who care for them I too have had to reflect on my own developing understanding of the use and importance of embodied practices (see Chapter 3 section 3.4).

Embodied practices described here, have also been used by me throughout as a means of communication which have contributed to: improving mobility; affirming identity; supporting affective communication; increasing well-being and the range, depth and quality of care relationships generally. This previously neglected area of study has the potential to make a valuable contribution to current thinking and practice in this area; and also through the process, to my own development as a researcher/practitioner working in the dementia care field in the context of DMP.

Before presenting the key aims, it is necessary to sketch out a context for this thesis set within a number of different disciplines, each relating to and influencing the other. I use the image of 'threads' here, like the 'weft' in traditional weaving that intertwines around the 'warp': each starting out as single threads: each approaching from different directions: each influencing the other by way of how they interlock: each making a 'weave' or plait: each individual thread creating something new and recognisable in the 'weave', where before there was only the raw material. This image also refers in a psychological sense to how meaning is created, or co-created. By this I mean how the individual fragments or threads of retained memory for the person can be triggered, re-membered or somehow laced together, creating a sense of wholeness out of single unit, by way of relationships developed and maintained between the person living with dementia and the person(s) providing the care. The sense of co-creation comes by way of how re-integration and remembrance can be greatly assisted by the extent to which the 'other', in this case the care-staff, can reach the person with dementia. Form emerges out of void, something out of nothing and sense out of non-sense. One of the 'threads' presented here is a requirement to better

understand the person living with dementia in the context of contemporary dementia care practice. What is their experience of care like and how might this be changed or influenced by the use of DMP as a creative, therapeutic, embodied and mediating factor in the quality of that care? To this end, Chapter 2 draws on three further threads, namely Anthropology, Dance Anthropology and Ethnography that to the best of my knowledge have not been applied before to the study of people living with dementia. These disciplines have all been used extensively in the study of indigenous peoples and cultures around the world and a call is made in this chapter for a new approach to ‘otherness’, ‘strangeness’ and ‘difference’, as expressed through the person with dementia. This new approach comes framed by an anthropologically generated perspective described here as, ‘Building a Bridge of Understanding’. The intention in Chapter 2 is also to recommend that dementia care practitioners, clinicians and care-staff and carers use insights gained from anthropological study in order to help ‘build bridges of understanding’, between themselves and people living with dementia; helping them to better accept, and work with, potential ‘strangeness’, ‘otherness’ and ‘difference’. This means making these latter aspects of the dementia condition, the *norm* in care practice and communications, rather than the exception. It also represents a paradigm shift away from current thinking and places the onus on those providing the care, to be much better equipped psychologically, emotionally and experientially in reading the ‘runes’ of dementia and making more sense and meaning out of the so-called ‘non-sense’. This approach to the revelation of meaning: how best to make sense out of so-called non-sense, expressed here and throughout this thesis, I understand to be one of the most vital aspects of working from a more

psychologically informed base, in better communicating with, and meeting the needs of those receiving care.

The next thread explored in this thesis and described in Chapter 3 is about better understanding dementia. How is the dementia condition currently viewed and experienced? What is meant by it, how is it defined and how do these different viewpoints influence the care of people with dementia? There is also a need to better understand the context of care and the environment within which these disciplines and people interact in this study, namely on an NHS Ward. Chapter 4 takes the thread of Dance Movement Psychotherapy, by way of investigating its roots and origins as an embodied practice, presenting the development and use of DMP with older people from historic to contemporary practice, and latterly with older people with dementia. DMP is a crucial aspect of this study and a thread that weaves through it all; this chapter aims to place it within both an historical and a contemporary context, arguing for its application here in relation to answering the aims presented in this study.

The aims raised here began to be asked when I started working with older people in Sheffield in 1985. Since then I have had a growing interest in and understanding of the work with a particular focus that is above and beyond the purely professional. There is a strong vocational element to this study, as I realised that I was being touched in a deeply personal way by what I saw, felt, imagined and experienced. I could not help having this reaction as I became increasingly immersed in the work while at the same time vulnerable to the care experience itself and its impact on me. This aspect puzzled me, as I noticed how the dementia syndrome expressed itself



differently in each person I worked with and how I needed to respond differently to each one. Throughout that time, I witnessed no common or collective descent into total brain disintegration; rather I observed that each person seemed to experience the disease in a uniquely individual way. However cognitively impaired and physically disabled, I became aware that each person still retained many abilities, especially creative and emotional ones, which enabled him or her to function, albeit to varying degrees, even in late-stage dementia. These discoveries I later found echoed by Sacks (1985) in the initial quotation, and they have become a touchstone for me in relation to the aims presented here in this study. The work I was doing concerned the re-discovery of personal resources and talents that were unique to the person, for example, the ability to move, to dance, to sing, to tell stories and to re-member life experiences from the past. I realised that this was a re-membering process, meaning that it was still possible in spite of great cognitive loss for people to re-connect with skills and abilities, stories and memories that they thought they had lost access to, and by way of that gaining confidence in the present moment regarding the skills they still possessed. They could do so again by way of engaging with these ‘embodied practices’ (see Chapter 3 section 3.4) that took place within the context of the care environment. I realised that the context was as important as the work itself, including the short and long-term effects and possible increases in observed well-being and reductions in ill-being. I wanted to know more about these influencing and triggering factors on the person, especially on those doing the caring including the care-staff.

I have come to the conclusion during the course of my studies, these past nine years, that the dementia condition is in essence an existential one, requiring an existential

approach - individually tailored and orientated to the person. Indeed, there are no limits to finding ways to enable connection, relationship and meaning expressed verbally and non-verbally, returning to the person with dementia a sense that they are not lost in a fog or trapped in a void after-all. The existential pain of the condition can be eased somewhat by taking an existential approach aiming to diminish the suffering without diminishing the person. While there has for me over the past twenty-two years been a professional/vocational journey of personal significance, there has also been major change in the provision of care services. There have been important developments in both the culture and quality of care for the better, although there is still a long way to go. One of the major influencing factors has seen moves towards the development of a more bio-psychosocial approach, away from the predominantly bio-medical. This has taken into account other equally important factors, including psychological, social, environmental and societal influences that also affect quality of life, the quality of care and outcomes for all involved. This more humanist, more effective and bio-psychosocial model in the care of people with dementia is described as 'Person-Centred Care' (Kitwood and Bredin, 1992a: 247)), and it represents another thread in this study with its roots, developments and challenges, described in some detail in Chapter 5.

This study has three specific aims in order to better understand the non-verbal, affective aspects of the relationship between care staff and people with dementia in the context of the care environment and the ways in which people living with dementia and those who care for them are influenced and affected by DMP. The aims therefore are:

- 1) To observe the effects on well/ill-being of people with dementia participating in a DMP session.
- 2) To identify the embodied practices occurring during the session and their impact on both people with dementia and their care-staff.
- 3) To identify the impact of the DMP session on the care-staff.

The aims above are discussed in detail in Chapter 6 including other important fieldwork aspects of the study. These include how they will be answered, the data gathered, presented and analysed, together with the ethical issues involved. In Chapter 7, the data is analysed and discussed in detail in relation to the responses of both group and individuals taking part in the study. Chapter 8 will then attempt to draw all the different threads together, by way of looking to the future and presenting a more embodied framework for the development of dementia care. I will draw on all the material presented, including the VTR, to make a call for an approach to dementia care that I am calling 'Creative Care'. It will set out a new approach, rather than a model, which will seek to enable care-staff to engage in more embodied and creative ways with the most confused and most vulnerable people in society. A call will be made for care-staff to be helped to work much more creatively, more imaginatively and relationally in finding and weaving together the remaining threads, metaphorically speaking of 'warp' and 'weft' in the lives of the people they are caring for. As Ward et al (2002b: 36) have reported, '(a)s the recipients of care, people with dementia are best placed to comment upon the need for change. The challenge ahead lies in finding the best possible route to supporting their struggle to be heard'.

## **Chapter 2**

### **Building bridges of understanding**

#### **2.1 Introduction**

I argue that important links can be made between the theory and practice of anthropology and the use of the arts including DMP in the care of people with dementia. This chapter will draw attention to anthropological and ethnographic perspectives in relation to my own work and that of others in the field including writers, artists, arts therapists and dementia care specialists. It will reflect on insights, ideas and practical tools gained from studying anthropological and ethnographic literature, transposed in relation to arts and dementia. It will identify a number of important ideas including the concept ‘building a bridge of understanding’ (Schultz and Lavenda 1990: 58). It will explore anthropological notions of subjectivity (see section 2.3) and inter-subjectivity (see section 2.3) together with the importance of reflexivity (see section 2.3) in practice and research (Schultz and Lavenda, 1990). It will also discuss an important innovation in the evolution of contemporary anthropology with the move, started in the mid 1980s, towards an ‘anthropology of the senses’ (Howes, 1991, cited in Classen, 1997: 407). This branch of anthropology brings an awareness of different kinds of sensory modality that are important and relevant in ethnographic research (Stoller, 1989; Howes, 1988, cited in Ravetz: 2001; Feld and Keil, 1994; Ingold, 1992, cited in Ravetz, 2001). Of particular interest in the dementia care sector is the parallel development, seen particularly over the last ten years, of the evolution and application of a new ‘sensory oriented’ approach to

care. It is described in the dementia care literature as ‘The Senses Framework’ (Davies et al, 1999, Nolan, 2007, cited in Nolan et al, 2008, Nolan et. al. 2006 cited in Nolan et al, 2008) and the framework is closely linked with the development of Relationship-Centred Care (Tresolini and the Pew-Fetzer Task Force, 1994). ‘The Senses Framework’ argues for an approach to care that focuses particularly on the quality and types of relationships between all involved. This relatively new sensory-based framework, based on a set of six senses, requires that care-staff in residential homes, day-centres and hospital wards, need to be better able to tune in to the person with dementia in more relational, sensory and psychologically-oriented ways. The founders of the ‘Senses Framework’ (Davies et al, 1999, Nolan, 2007, cited in Nolan et al, 2008, Nolan et. al. 2006 cited in Nolan et al, 2008) in dementia care were not influenced by the developments in ethnography and anthropology from the mid 1980s on, however there are interesting parallels between the two.

Anthropologists refer to the importance of better understanding the cultural ‘other’ by offering practical and theoretical ways to better understand difference. In the dementia context, therefore, this cultural ‘otherness’ or ‘strangeness’, expressed by the person with dementia, can be re-framed not as something alien and alienating, rather as a valuable and important expression of difference and diversity in human communication and experience. This chapter presents anthropological concepts, ideas, writings and approaches in coming to know ‘the other’ in human society, helping build bridges of understanding between self and ‘other’ and in the dementia context between the person with dementia and those who care for them.

This chapter will also refer to the way in which both ethnographers and anthropologists ‘seek to understand the meaning of the webs of significance humans spin from their perspectives’ (Hanna, 1990: 116, see section 2.7).

## **2.2 The importance of ‘building a bridge of understanding’ between self and other**

In this section I will focus on the idea of ‘building a bridge of understanding’, between self and other, an important metaphor that Schultz and Lavenda (1990: 58) describe as the foundation on which anthropologist and informant may better understand each other. This is also what Rabinow described as ‘the dialectic of fieldwork’ (Rabinow, 1977: 39) in which anthropologist and informer try to figure each other out. Rabinow is regarded as an important pioneer in ethnographic fieldwork and writing because of ground-breaking work in Morocco in the late 1960s. The practice of DMP provides much scope for building bridges of understanding between what is known and what is not known about a person with dementia. For example, we as clinicians and care staff aim to provide high-quality care and we have a responsibility placed on us by our employers and within our own professional codes of conduct (ADMT UK, 2003), to do that well; that means being able to make sense of vital verbal and non-verbal communication that at first may seem like non-sense. Making sense of vital verbal and non-verbal communication also means being able to appreciate people’s inner worlds, their inner landscapes and the meaning and importance attached to them. In effect we are attempting to build bridges of understanding between the known and the not yet known, between that which makes

sense and which does not, in order to provide better Person-Centred Care (see Chapter 5). Anthropologists also have to find ways of relating to and making sense of what at first may seem very perplexing in a different culture, able to represent the constituent parts of the language or culture without being patronising or condescending; and yet over time and on reflection, understanding begins to emerge as distinct and important. Also in this context they need to be able to make sense of people's behaviour's, their feelings, thoughts and ideas in holistic rather than isolated or reductionist ways (Hanna, 1990).

In a literal sense, a 'bridge' connects two pieces of land that are separated by a natural feature in the landscape such as a river. Metaphorically, in communication with a person with dementia, a 'bridge of understanding' could be understood as the vital link that helps establish relationship and connection between the therapist/carer and the person with dementia. This 'bridge' is formed through insight or intuition, skill, knowledge or experience that helps make sense of perplexing fragments of verbal and non-verbal communications and memory. This process of linking or 'making sense of' is relational and could be facilitated by a care worker skilled in communicating with a person with dementia and motivated to do so. With verbal language deteriorating to a point where the individual has great difficulty in communicating, any supporting action / behaviour takes on great significance in the process of care. If the essence of communication is about conveying meaning from one person to another, then this could mean the difference between a person being heard, understood and the meaning acted upon, or its opposite, with a resulting negative impact on observed well-being. Gibson was unequivocal in her Tom Kitwood Memorial Address that doing nothing

sends out a very strong message, a powerful negative message that conveys to the person with dementia that they are not worth bothering about, and that in turn causes further anxiety and further withdrawal: ‘The risk of doing nothing and leaving people in their increasingly isolated, socially shrinking, boring worlds...is morally and professionally untenable’ (Gibson, 1999: 20).

### **2.2.1 An example of ‘building a bridge of understanding’**

An older person called Martin with severe frontal lobe dementia and a very poor short-term memory was a patient in a Continuing Care Ward in a NHS hospital. During a programme of group based DMP sessions, Martin was enabled to make a connection, or ‘bridge of understanding’, between the music of Al Jolson and his own past memories. This gave the participant particular pleasure and contributed to raising his observed well-being during the session I was facilitating (see Chapter 7 section 7.2.2).

I can only hazard a guess at what was taking place from the point of view of the subjective experience of the older person and reflect on the extent to which this was an isolated incident or something more significant. Three important elements can be identified out of many. One was the past knowledge/experience stored in the person’s memory at an earlier point in his life, involving long term or *procedural memory*; the second concerned the *potential* for how that memory would manifest in the present moment; the third was the *trigger* that brought it back to life. What triggered it appeared to be a sequence of questions, beginning with my asking Martin a question about the kind of music he liked. He did not respond immediately, so LC who was sat



next to him, followed this by asking what his favourite song was and what he sang when he used to go out clubbing with his wife W (see Appendix A, 11.10am). At this point he remained silent looking down at his ribbon-stick. I then looked directly into his eyes and asked him if he went dancing? Arthur hearing the question, sat next to me on my left then replies with the answer Blackpool. Martin almost in a whisper then says the word 'Johnson' to me and I repeat this back to him, trying to understand if this is what he meant, at which point he manages to say in a whisper 'Al Jolson'. I then acknowledge this with a sense of relief that we have been able to make a connection and reprimand Martin at the same time for not saying this earlier (a comment I regret with the benefit of hindsight). I then began to play the CD of the music of Al Jolson and noticed that Martin began to move and respond in an embodied way. Another member of staff GB, witnessing this, without hesitation invited him to stand and dance with her, which he did. The Dementia Care Mapping (DCM) scores (see Chapter 7, Section 7.2.2) for this time-frame clearly evidenced significant positive person work in DCM terms.

During this episode in the session both members of staff and me were acting verbally, non-verbally and psychologically as 'bridges of understanding' for Martin. Verbally because the content of the questioning process gradually involved more personally and emotionally relevant material, including references to his wife Winnie and what they used to do on a night-out clubbing provided by LC. Non-verbally because GB and me, both noticed and were accurately able to help make the bridge between his embodied responses, clearly demonstrating pleasure and movement, and the music once it began to play. A bridge was made in a psychological sense between his past

memory of the musical importance of Al Jolson to him and his present moment recognition and re-membling of it through the playing of the music. It was a ‘trigger’ enabling him, during the session, to become both physically and psychologically more engaged and involved where previously outside of the session that had not been the case. For Martin, the resulting movement experience appeared to give him considerable pleasure and enabled him to find several words to describe the experience. For a man with very poor speech and vocabulary this was significant and is supported in a study by Hokkanen et al. (2003) investigating the application of DMP in dementia care, who found in a randomised controlled trial that ‘the dance/movement group seemed to have a favourable effect on language abilities’ (op.cit.: 576). Here was also significant evidence for the importance of ‘embodied practices’ (see Chapter 3 section 3.4) including in this instance eye-contact between Martin, LC, GB and me. Also there was a holding of hands, a side-to-side swaying movement and a clear sense of engagement and involvement in the dance-movement or embodied activity that followed. It is significant also in the context of Martin’s experience that care staff used their own ‘embodied selfhood’ (Kontos, 2005) in making meaningful connections with Martin. These were empirically found to have had an impact on Martin’s sense of agency and observed ‘well-being’, as evidenced through analysis of both VTR and DCM scores.

Whilst having a pleasurable experience is valuable in any context, to someone with very limited speech and cognitive skills, the ability to communicate, convey meaning and take part in any activity takes on even greater significance, and according to Killick, it is ‘a matter of life and death of the mind’ (Killick, 1997a: 14). He, like

Gibson (1999) reported above, meant that in spite of problems in communicating, 'failure to make progress in overcoming these can have serious consequences for the caring process' (op.cit.: 14). These include a sense of personal isolation, disempowerment and a tendency for others to deny the concept of 'Personhood' (Kitwood and Bredin, 1992a: 274) to the individual (to be discussed later in Chapter 5, Section 5.3.1). If individuals have insight and can express or be helped to express it, then according to Killick they have a far better chance of having their needs met within the care process. Finding ways to support the individual to communicate in spite of their communication difficulties and care staff to hear, understand and respond appropriately and well is of central importance in their care and welfare. Ward et al (2002b: 36), in a research review which investigates dementia and communication, conclude that, '...(a)s the recipients of care, people with dementia are best placed to comment upon the need for change. The challenge ahead lies in finding the best possible route to supporting their struggle to be heard'.

I take up Ward's important challenge in wanting to find the best possible route to supporting the person with dementia's struggle to be heard. I have argued here that the anthropological concept of building a bridge of understanding between self and other is both a useful metaphor and practically important in helping frame and make sense of perplexing fragments of language or behaviour in the care environment. It also has a practical application in the training and development of care-staff and other care professionals, in finding different and individualised ways to improve communication and relationships, responding effectively and well to the many challenges presented in dementia care.

### **2.3 Aspects of anthropology and ethnography relevant in the dementia care context**

There are terms reflecting different methodologies within anthropology and ethnography including processes of ‘writing-up’ and fieldwork that need defining, since my aim is to identify, refer to and use them in different but cross-cultural contexts. It is also important to remember that while both disciplines are very closely linked, my main purpose here in this chapter is to draw on insights and knowledge from both and apply them to the dementia context without getting lost in detailed analysis of either.

Anthropology is an academic discipline concerned with the study of human-kind throughout the world, at all times and in all places. Ethnography is a closely related discipline best understood according to Hammersley and Atkinson (2007), as a reflexive process where the research itself is acknowledged as a part of the world it studies. Key features of anthropological study include processes of: selection and sampling of cases: access and ethical problems: observation and interviewing: recording and processing of data-analysis and writing research reports (op.cit.). This is echoed by a definition according to the Encyclopaedia Britannica that refers to ethnography as, ‘a descriptive study of a particular human society or the process of making such a study’ (Ethnography, 2006: 9033138).

There are many different aspects to the study of anthropology and Kuper in the Social Science Encyclopaedia defines ‘the central issue in anthropology’ as being ‘human variation’ (Kuper, 1996: 22). This definition is of particular importance to my

argument because it takes 'human variation' as the key element in anthropological study. Anthropologists are studying and learning about 'difference' and 'otherness' in human culture and society throughout the world and they are therefore well placed to offer insights into the expression of 'otherness' and 'human variation' as expressed in contemporary dementia care practice, not just here in the UK but around the world. The study of dementia syndrome and of Alzheimer's as a specific condition began with the work of Alois Alzheimer at the turn of the twentieth century (see Chapter 3, Section 3.2). The roots of anthropology, however, go back to colonialism in the mid-nineteenth century and before, and represent a much longer timescale in which to gather learning and knowledge about the different cultures, societies and traditions in which people live. Since the middle of the twentieth century anthropology has become a collection of increasingly diverse and specialised fields with growing acceptance of anthropology 'at home', or of 'the other' within, rather than it taking place where it began in 'exotic', remote locations. More recent specialised fields have come out of Applied Anthropology from the 1920's onwards (Kuper, 1995), such as Medical Anthropology, Linguistic and Psychological Anthropology and Dance Anthropology (Hanna, 1990), all in the United States.

There are now contemporary anthropologically based comparative approaches, practices and techniques to examine the context and the culture of the environments in which people live. Anthropology involves human beings studying other human beings, and while anthropologists are trying to understand the subjects in a particular culture, the subjects are trying to understand them; the implication is, therefore, that the fieldwork aspect of anthropology involves intimate encounters between human

beings (Schultz and Lavenda, 1990). This view of how the anthropologist and indigenous people make sense of each other is supported by what Grau writes of the fieldwork experience with the Tiwi people in Northern Australia, ‘(b)oth...are trying to make sense of the other: this requires insight, empathy, imagination, perceptivity and humility on both sides’ (Grau, 1999: 167).

There is a process aspect of ethnography of most relevance in the context of this chapter for the ways in which processes/methodologies have been developed over time in response to particular anthropological and ethnographic challenges. The learning and knowledge contained in them can be theoretically and realistically transposed into the dementia care setting. For example the challenge about how to become more rigorous in both collecting and analysing data in the field was addressed by Malinowski, a key early pioneer. He was the first to develop and use what became known as participant-observation, in an important piece of work with Trobriand Islanders between 1914 and 1916 (Ethnography, 2006). **Participant-observation** required the total involvement of the ethnographer in the life of the people or culture being studied. Dementia care staff can learn from this for example to immerse themselves much more fully in the life and culture of their own settings in order to be able to better understand it. This means a process of engagement in the lives of people with dementia that goes beyond the basics of everyday care tasks and care practice. It is more embodied and more fully involved with the person socially, emotionally and psychologically as well as physically. To do this well, there is a need in the anthropological sense to seek to understand how others understand, to reflect on and make sense of these ‘differences’ expressed in neurological, psychological,

physical and behavioural changes for the person with dementia. The personal, professional and human qualities needed are insight, empathy, imagination, perceptivity and humility on **both** sides, as Grau has argued, together with a willingness to explore the possibility for more intimate human encounters. These qualities identified initially by the anthropologist are of great significance for the care-staff and arts psychotherapist, in better understanding the day-to-day experience of care for the individual, while at the same time being better able to provide a more responsive, intelligent and informed level of care service.

**Reflexivity** is another important concept and means that the anthropologist /ethnographer must reflect on the way they think about people, culture and society. In relation to my own practice this means I must be prepared to think about how I think; to consider for example the values, attitudes and beliefs I hold about the people I work with and they about me. What are the culturally received ideas related to age and ageing that impact on my work and communications? What assumptions, for example, do I have and share with my patients about how we communicate non-verbally as well as verbally with each other and its impact on the quality of care provided by the Dance Movement Psychotherapy Service? How can I investigate more fully the nature of embodied practices in relation to DMP? I will argue that one particularly important cross-cultural link between dementia care and anthropology is that of being able to question and to wonder; which according to some anthropologists should *replace* the scientific concern for objectivity in processes of anthropological study and research (Schultz and Lavenda, 1990).

**Subjectivity** is also an important aspect of anthropological and ethnographic study and refers to the sensory and embodied nature of the individual, their individual way of seeing the world and the phenomena contained within it. Subjectivity extends to how individuals make sense of and invoke meaning from their own experiences, which is in direct opposition to the scientific notion of objectivity, which seeks to separate human values and subjectivity from a deterministically proven reality. The focus of the fieldwork experience extends to asking questions about the range of subjective and inter-subjective meanings shared by those events, people and situations informing the research. How, for example, can both ethnographer and social researcher enter into dialogue about these reflections and experiences exploring differing meanings, viewpoints and perceptions? These are important concepts in relation to the content of this chapter and will be developed in other parts of the thesis.

**Inter-subjectivity** is dialectical referring to that which takes place in the space or the 'field' between the subjective experiences of two people for example. Practically it can enable the dementia care worker to understand more fully the complexity of the communication, relationships and inter-relationships taking place. A simple example of the inter-subjective can be clarifying with the person that both of you have understood the communication that has just taken place – 'do you mean you would like me to talk quietly?' for example. For the person with no verbal language and other disabilities or sensory losses this can be much harder and more complex to achieve, requiring a great deal more sensitivity and skill. A more complex and embodied example would be use of a DMP technique called 'Mirroring' (Levy, 1992,



cited in Shustik and Thompson, 2001: 53, see Chapter 4 section 4.2) which aims to enter and remain for a time in the inter-subjective and embodied space between people. This technique can be of great help when in the presence of a person in the more severe stages of a dementing condition unable to communicate verbally, where the clinical need may be to elicit and maintain communication and relationship however possible.

Nolan et al (2002), in research with family carers, call for a more empowering and inclusive model of research and practice focusing on the importance of relationships (inter-subjectivity) between people with dementia and their family carers. They argue that the most effective interventions in dementia care over the past twenty years, apart from drug advances, have been and will remain for the foreseeable future the development of services supporting people with dementia (Nolan et al, 2002). In their conclusion, they argue that there is now in the field a more widespread recognition of the essential subjectivity of dementia; that a truly inclusive vision for the future of dementia care practice and research should see the development of a much more *relational* model of care and one that 'must involve greater attention to the inter-subjectivity of dementia' (op.cit.: 206). Relationship-centred Care (RCC) (Tresolini and the Pew-Fetzer Task Force, 1994) is an important contemporary development that acknowledges this relational aspect and which 'captures the importance of the interaction among people as the foundation of any therapeutic or teaching activity' (Tresolini and the Pew-Fetzer Task Force 1994, cited in Nolan et. al. 2002: 206). RCC therefore supports the importance of inter-subjectivity and its relevance in

helping improve the quality of relationships and the design and delivery of improved support and services for people with dementia (see Chapter 5 Section 5.4).

## **2.4 Anthropology of the Senses**

Contemporary ethnographic research with its emphasis on participant-observation has been changed irrevocably by the writings of Marcus and the publication of a contemporary critique of Malinowski's work and legacy, published by Marcus and Clifford called 'Writing Culture' (Marcus and Clifford 1986, cited in Grimshaw and Hart 1996: 8). Marcus and Clifford argued convincingly that Malinowski and his followers, while credited with making major innovations in fieldwork in the British School were, in the light of contemporary anthropological thought and research, also a hindrance to the development of contemporary approaches. The details of this argument and the methodological challenges presented by this 'emblematic text' (Ravetz, 2001: 101) can be left out for the purposes of this chapter, however the mid 1980s witnessed a drive by some anthropologists for a more sensuous anthropology that was embodied and engaged; see for example Stoller, 1989, Howes, 1988, cited in Ravetz, 2001, Feld and Keil, 1994, Ingold, 1992, cited in Ravetz, 2001. Collectively their approaches were more open, eclectic and expansive towards the full range and representation of human experience. It was not dependent on text and writing and again represented, according to Ravetz (2001), a major methodological division between the text-based approaches characterised by 'Writing Culture' and those of this 'anthropology of the senses'. Feld and Keil (1994), for example, working through

sound and music but writing here about communication, show a profound understanding of its complexity:

Communication then is not located in the content communicated or the information transferred...it is not just the form of the content nor the stream of its conveyance. It is interactive, residing in dialectic relations between form and content, stream and information, code and message, culture and behaviour, production and reception, construction and interpretation. Communication is neither the idea nor the action but the process of intersection whereby objects and events are, through the work of social actors, rendered meaningful or not ' (op.cit.: 78).

Feld and Keil propose here that communication exists at a place of intersection or meeting, an in-between place and that the focus is always on a relationship, not a thing, object or entity and that its origins are 'multi-dimensional' (p.78). This reference to communication as a 'process of intersection', an in-between place, is important as it echoes my earlier argument concerning, 'building a bridge of understanding' (Schultz and Lavenda 1990: 58) between care-staff/therapist and the person with dementia. The communication itself, taking place on that metaphorical 'bridge' or intersection, is arguably multi-dimensional including relational, interactive, dialectical, metaphorical, meaningful and embodied aspects, all taking place at the same time. How possible is it then to understand it by breaking it down into its constituent parts without negating or destroying its embodied, living and relational

properties? I would argue that whilst it is not possible to be reductionist towards the process and constituents of communication, a more sensory, embodied and relational orientation coming from contemporary anthropology brings new opportunities for furthering knowledge and insight. From an embodied perspective this view is supported by Hanna, (1990) an experienced and senior Dance Movement Therapist and Dance Anthropologist, who argues that body movements rarely have meaning taken separately and out of context as the whole picture is crucial: ‘...the actual meaning of body language is found through seeing the whole pattern in the context of the individual mover having a combination of personal, cultural and environmental experiences’ (op.cit.: 117). These new approaches encouraging appreciation, knowledge and awareness of different kinds of human sensory modalities provide an important framework for better understanding the subjective, the inter-subjective and embodied worlds and how we could as dementia care practitioners learn from them. We cannot afford to ignore this language of sense and sensibility, a large part of the rich and embodied nature and complexity of human experience; otherwise, we may by default, miss a vitally important opportunity to open up new horizons for relating to and being with people who do not communicate by and large through speech. Hanna (1990) also argues that: ‘(e)ach kind of language adds a unique dimension to the message’ (op.cit.: 117).

The researches of these sensory-oriented contemporary anthropologists give us permission to explore for ourselves the dimensions of human experience that are not either immediately obvious as in dementia care, or that have previously been overlooked. They are of great importance in the development of my argument in this

chapter and throughout this thesis, that if we are to improve the quality of the lives of people experiencing dementia then we have to be better able to make, create and sustain the kinds of care/human relationships that focus on remaining sensory-based abilities, going by way of all the senses.

## **2.5 The importance of the fieldwork experience: gathering data and understanding dementia as a language**

This section aims to link the previous references to an anthropology of the senses with the importance of fieldwork, together with examples of where and how this is relevant and useful. The anthropologist is required to gather data about a culture and to understand and make sense of language as communication expressed within the culture of that society. More specifically, Hanna (1990) argues that because of its comparative, cultural and holistic approaches, an anthropological perspective is ‘critical’ in working effectively with the ‘unserved and the underserved people of other cultures’ (op.cit.: 115). She says that recognising different cultural patterns can lead to adaptations enhancing the theory and practice of DMP. This perspective also holds true for people with dementia who I would argue are ‘unserved’ and ‘underserved’ (op.cit.: 115). Hanna goes on to argue that we have to learn to question our own assumptions and apparent facts and observations in order to discover the subjects point of view – or in my case the point of view of the person with dementia, the care-staff and relations between them. Implicit in Hanna’s argument is that as a practising Dance Movement Psychotherapist in recognising different cultural patterns

and learning to question my own assumptions and apparent facts in a dementia care context, I can enhance the theory and practice of DMP.

How does an anthropologist make sense of a language that may at first seem unintelligible? Firstly, they are required to spend time in that society, gathering information about culture and language using various fieldwork methodologies that have been developed over the years to fulfil this function. Here are some techniques in relation to the process of observation that are of special interest.

The fieldwork experience includes keeping different types of notes and according to some scholars these notes can have different and important functions: ‘scratch notes’, ‘field notes’, ‘filed notes’, and ‘head notes’ (Sanjek, 1990 and Fernandez, 1993, cited in Grau, 1999: 164). ‘Scratch notes’ are jottings made on the spot then broadened out into ‘field notes’ at a later and quieter time; ‘filed notes’ are notes that are organised and reconstructed; and ‘head notes’ are those that never get written down but remain in the ethnographer’s head to inform their writing at a later date. According to Schultz and Lavenda (1990) ethnographers are obliged to interact closely with the sources of their data. In my case the sources are the people with dementia themselves, those who care for them, those who manage the care staff and other sources of knowledge and experience that take this study forward including my own DMP colleagues and literature. For example, interaction within an anthropological perspective involves dialogues between researcher and co-researcher. People with dementia and their care staff are my co-researchers, and together we make patient and painstaking collaborative attempts to sort things out, to piece things together.

The following is an example of how an ethnographically informed ‘scratch note’ was transformed into something more important as I was able to reflect on it in greater detail. It is also an illustration of how a person with severe dementia, with very little left by way of language and awareness of space and time, has created and memorised an extraordinary little rhyme.

During a group DMP session in the summer of 2006 held at a Day Unit where I work, a member of the group coming for the first time recited a little rhyme she had made-up. She was a woman who was 86 years old in the later stages of a dementing illness and with very little language left. The following is the rhyme or mantra she repeated to herself regularly throughout the day and to anyone else who would listen. I was able to jot it down quickly on the back of my session evaluation notes, which I would describe as a ‘scratch note’ (her identity is protected):

“I’m Doris Sarah Loxley and I’m lost in a fog, so we sent Willy a St Bernard’s Dog who found me and brought me safely home, so we gave him a big juicy bone.”

Session Evaluation Notes (Session No.86.13/7/06)

Here is metaphor, symbolism and meaning from a woman with very little verbal ability and language still available to her. As a result these words take on great significance for her. Later on while reflecting on these words, using the idea of reflexivity referred to earlier and working with her again during subsequent sessions, I began to make a number of connections that helped me place these words in a

context in relation to their potential subjective meaning for Doris and the potential inter-subjective meanings contained within.

Metaphorically Doris is lost in a fog, the fog of a dementing illness. Kitwood has also used the metaphor of being lost in a fog, significant in his own researches, in attempting to describe the subjective experience of the person with dementia in a state of what he described as ‘unattended dementia’ (Kitwood, 1997a: 77). There is a dog in her psyche that knows the way home and can bring her home in spite of the fog of a dementing illness. This is not just any dog but a St Bernard’s, traditionally associated with monks who regard it as their spiritual duty to look after the dogs that save lost souls in the Swiss mountains; they also carry life-saving brandy in small casks attached to their collar. Doris can give the dog a name and thank it for bringing her home, by giving it a big juicy bone as a reward. Arguably, Doris consciously and non-consciously created a meaning system within the words that is both memorable and re-memberable in spite of severe neurological insult. From an inter-subjective point of view there is also an anthropomorphic aspect of her psyche symbolised by the dog that knows the way home through the fog and in a symbolic way supports her as she goes about her everyday life. I discuss the importance of the symbol and its function later in this thesis (see Chapter 4 Section 4.6).

From a cross-cultural and psychotherapeutic perspective, my work is by way of attempting to communicate with the parts of her psyche that are symbolically expressing through the rhyme. The rhyme is supportive of, and connected to her sense of identity and observed well-being, expressed symbolically and



anthropomorphically by the St Bernard's Dog – the animal that helps find her in that lost and foggy place. Doris experiences pleasure whenever she says these words to herself or others; this is evidenced by her smiling at the same time and is reported in my scratch-notes (Session No.86.13/7/06). The words and their meaning are comforting and vital to her sense of herself and her personhood; they take on an even greater significance when I consider that they represent for her nearly all the language that is left.

Unfortunately because of the nature of her illness, her vulnerability and confused state, I have been unable to explore, verify or even discuss the meanings I have attached to this poem; also their accuracy in relation to my own subjective understanding as described here. I have been able to ascertain from close family members or other relevant informants, that this was indeed her made-up rhyme and not copied or alternatively sourced. Essentially I am left wondering about these words and unlike the ethnographer, I cannot check out the different cultural meanings with my 'informant'. How did Doris create them, what aspects of her life and experience crystallised in that form? Why should I as a Dance Movement Psychotherapist have chosen these words to focus on and not her movements? Why was I drawn to them? The dance and movement medium is not particularly natural for Doris; however, she becomes animated in her body whenever she says these words as if the very sound of them and the rhythm in them is comforting and important. I have learnt this important rhyme and found it helpful within our therapeutic time together to say it with her when she struggles to remember it herself. I am therefore able to give these words back to her helping her remain in contact with them; ones that I would argue have

become essential to her own 'Personhood' (Kitwood and Bredin, 1992a: 274). I am also aware that by taking an 'inter-subjective' position and witnessing the response to this giving back of her own words, I (the bringer of these words) am immediately validated by either a warm and affectionate smile or often by her saying, 'you are my dear friend, my dear dear friend, I love you and I have always loved you' (Session No.86.13/7/06). Following the interaction that has been repeated on many occasions, I am left with a profound sense of the importance to Doris of the rhyme and this communication held between us. In the process my informant has been able to communicate emotionally, verbally and non-verbally (by holding my hand at the same time) matters of great significance to her. I have psychotherapeutically been able to witness that fact in the dialectical, inter-subjective 'process of intersection' (Feld and Keil, 1994: 78) that we created; and where we quite naturally built 'bridges of understanding' (Schultz and Lavenda 1990: 58) between us.

In taking this rhyme to my regular sessions of clinical supervision with an Analytical Psychologist, I was able to make further cross-cultural parallels resulting in the creation of a 'field note', which was made at a quieter time. I was able to explore the notion that meaning-making for a person with dementia is not necessarily about making sense, and to reflect on the fact that one might be out of one's mind but is one out of one's soul as well? (supervision field note 3/8/06). I now incorporate a section in my session and evaluation notes to capture words, phrases or comments about how the session is experienced by those taking part in their own words, which might otherwise be lost. In working with Doris during later sessions, I realised that the decline in her ability to remember vocabulary and formulate words meant that even

this little rhyme was gradually being lost to her. It was therefore of even greater significance to her that these words should be captured and returned to her in a way she could best understand, without being yet another aspect of her 'personhood' that gets lost.

Another basic tenet in anthropology is that feelings, thoughts and actions should be examined, and examined not as isolated bits and pieces but in a holistic or systems context (Hanna, 1990). One example of this in the dementia care field is a fairly recent and important study involving the analysis of over one-thousand hours of videotape where researchers were able to identify what they described as, 'characteristic patterns to communication in dementia care' (Ward et al, 2006a: 28). It was found that little support exists in care settings for staff negotiating and managing the emotional challenges of their work. Staff described struggling to interpret the outward signals and indicators of the inner worlds of the people they care for. They went on to suggest that care staff are indeed equipped with the capacity to read and respond to emotional (affective) communication even if they struggle to put this into words, but there did not appear to be a language readily available and accessible to care staff to capture the detail of what was being done. The study argued that overall in dementia care there were no systems that drew attention to affective communication being facilitated and understood by care-staff, with them also encouraged to record examples of it. They reported that a mechanism is required to support staff within care institutions to consider and reflect on these crucially important aspects of communication in order to improve their practice (Ward et al, 2006a). The 'mechanism' referred to here links again to the anthropological concept

of ‘building bridges of understanding’ (Schultz and Lavenda 1990: 58) between inner and outer worlds, between the emotional and the cognitive. Care institutions need to focus on how they are run and organised as well as on the training and development needs of care staff, in order to better facilitate the *improvement of communications* as a crucial aspect of dementia care (Ward et al, 2006b).

I argue here that the professional and personal experience of care staff struggling to understand and make sense of affective communication is an important and neglected area of study and research that anthropological insight, knowledge and experience may be able to take forward. We need to ask, for example, how we can improve affective communication and the care of people with dementia within the context of contemporary approaches in dementia care practice. Here are some examples drawing on anthropological practice:

- 1) We can remain touched, vulnerable and open to the fieldwork/care experience as reported by Schultz and Lavenda (1990) who write that ‘(i)f anthropologists leave the field unchanged, they may well have missed the field-work experience itself’ (p.57). In learning more about the affective world of the person with dementia, we as care-staff carers and therapists must remain open to be touched by and vulnerable to the experience. If we can do this, more is revealed about the hidden humanity of the person with dementia in an individual sense and also more about the hidden humanity and meaning contained within the dementia syndrome itself; including in an anthropological sense the inter-subjective relations between the person and their carer. Through the process of caring for, relating to and ‘being

with' the person in-depth, our own humanity as care workers and clinicians is also revealed, in a symbiotic way, to the extent to which we can allow ourselves to be touched by the ebb and flow of that communication (Coaten, 2002a). 'As we come to grasp the meaning of the other's cultural self, we simultaneously learn something of the meaning of our own cultural identity' (Schultz and Lavenda, 1990: 58). Stoller (1989), speaking from a more sensory and sensuous place, informed by repeated fieldwork trips to Niger in West Africa, argued that while sight as a medium for perception is privileged in western society, this is not the case for the Songhay. 'This fundamental rule in epistemological humility taught me that taste, smell, and hearing are often more important for the Songhay than sight, the privileged sense of the West' (Stoller, 1989: 5). The experience of sound is equally important in this regard and an analysis of naming practices used by Feld (Feld, 1996, cited in Ravetz, 2001), showed how the inseparability of the rainforest, waters and land are felt and imagined by the Kaluli to be like the flow of the voice through the body's contours. What does it mean in practice to allow ourselves to be touched and vulnerable to the experience of care, to the ebb and flow of relationship; much as the anthropologist is vulnerable to the fieldwork experience and the 'cultural other'? Fieldworkers must in the anthropological sense embrace the shock of the unfamiliar and of their own vulnerability if they are to achieve any kind of meaningful understanding of the culture of their informants (Shultz and Lavenda: 1990).

There is an immediate and important parallel here for care staff struggling to make sense of the world of the person with dementia, they too must experience their own

vulnerability and shock, in relation to trying to understand that world or the 'otherness' of the world of the person with dementia. In doing so they must also be prepared to reflect on the subjective and inter-subjective meanings contained within the communication and the relationship, even if they are not able to draw on or use the language of the fieldworker anthropologist in order to explain it. I would argue that care-staff, as evidenced by Ward et al (2006a) in their study above, do have the personal resources to make sense of affective communication, although they tend to do so in individual and didactic ways and outside of any recognised framework or language within which to express it. If one of my overall aims as practitioner/researcher is to improve affective communications in work with people with dementia, then it is necessary for care staff to be helped to understand that improving their affective communication means becoming vulnerable and open to the experience of 'otherness'. This aspect of becoming more vulnerable and open to 'otherness' or difference, means coming to know more about self by way of the other. It is fundamental to the work of the anthropologist and the psychotherapist and I argue also to the work of the dementia care practitioner. Our challenge is to build it experientially into staff development and training programmes. Mair (1980) describes the essence of this vulnerability most elegantly in words emotionally and psychologically congruent: '(i)n coming to know personally we will need to speak and listen in such a way that we can hear what cannot normally be spoken and dare to know through being intimately known' (op.cit.: 113).

2) We can allow ourselves to be changed by the fieldwork/care experience. Hill (2004) has articulated that not only did DMP make an important contribution to the

care of people with dementia within her own study, but also she was profoundly changed by the experience and by her own researches into the wider community including the social and cultural context that the anthropologist might frame as cultural relativity. As a Dance Movement Psychotherapist and researcher, Hill drew the important conclusion that in, 'tracking the barriers to person-centred care, I have had to move beyond the individual, beyond the institution, and beyond government, to the over-riding values and beliefs of the society in which I live, at the same time recognising the revolving interconnections between them...' (Hill, 2004: 287). She argues that while Person-Centred Care (PCC) (Kitwood and Bredin, 1992a: 274 see Chapter 5) has offered a more positive and validating perspective on the person with dementia and the philosophy of practice, much more radical change is necessary if PCC is truly to be person-centred and one must, 'widen the focus beyond the individual person to the community as a whole' (Hill, 2004: 287) with the realisation that people with dementia are not so very different from the rest of the human race. Hill had tried through a process of cultural relativity, in-depth examination and cross-cultural comparisons, to explain why her work as a Dance Movement Psychotherapist in a Jewish Care Home in Australia had not worked as well as she and others had at first thought. She found that there were many factors contributing to her conclusions and that in order to identify them she was required to travel theoretically, academically and anthropologically far outside the confines of the setting in which she worked. I have no doubts that in my research I am being required to do the same and in the context of this chapter, build bridges of understanding between contemporary anthropology and dementia care practice.

3) We can learn to appreciate the nature and importance of affective communication in our practice as care-staff, carers and arts therapists, each from our own perspective of training, experience and knowledge. We can be more reflexive towards understanding the nature and purpose of the communication, in expressing individual needs and desires on the part of the person with dementia; recognising for example, the special context of the formal care environments where this communication happens. Within formal care environments, research has highlighted the difference between the expectations of care-staff, where care tasks themselves were the predominant topic of communication, and people with dementia who were more interested in communicating current affairs, reminiscences, feelings, plans and hopes (Iwasiw and Olson 1995, Edberg et al 1995, Small et al 1998, cited in Ward 2002b: 34). It is clear according to Ward in his research review that the recipients of dementia care rarely go along with these care-staff priorities in communication and really struggle to initiate and maintain: ‘a socially oriented focus to everyday interaction’ (Ward, 2002b: 34). It is important, given this evidence, that all those directly involved in dementia care learn to be more open to sensually, socially and personally oriented communication expressed uniquely by every person with dementia in the care environment. This is in addition to current evidence by Ward of the predominantly task-oriented nature and context of communication in care (Ward, 2002b). As a Dance Movement Psychotherapist I am privileged that the DMP experience means that the majority of my communications take place within a therapeutic rather than a task-oriented context. I still have to work hard however, as does every accompanying member of the care-staff team to make sense of affective communication during the group or individual session.



## **2.6 Reflections on the importance of creative-writing in improving services for people with dementia.**

Underlying my practice is the belief that people with dementia have much to teach care staff, carers and all in society about their lived and embodied experience of an incurable disease; what it means to cope with the isolation and societal stigma that is involved; also what it means to live, everyday, knowing that you will forget what you know, or what you think you know. Significant challenges to the individual's self-esteem, independence and 'Personhood' (Kitwood and Bredin, 1997a: 274) are often involved. I have argued in previous sections of this chapter that anthropological insights and practices help create bridges of understanding that seek to improve communication and relationships, providing a richer and more sensuous experiential framework within which to better understand the syndrome and improve the quality of care. This next section seeks to investigate the impact of creative-writing in giving a voice to a person with dementia and as a means for expressing their experience of the condition. This I would argue also provides a rich and more sensuous framework for understanding the syndrome and is an important example that can help others to better understand it.

Recent evidence in the new and emerging field of arts and dementia indicates that people with dementia, even in the severest forms of the disease, are able to communicate through all the art forms, expressing themselves verbally and non-verbally through dance and movement (Coaten, 2000, 2001, 2002a, 2002b, Coaten and Warren 2008, Crichton 1997, Donald 1999, Gibson 2002, Greenland 2000, Hill

2001, Kindell and Amans, 2003, Palo-Bengtsson, 1998, 2000, Nyström and Lauritzen, 2005, Sandel and Hollander, 1995, Shustik and Thompson, 2001, Zachow, 1984), through visual art (Jenny and Oropeza 1993, Jensen 1997, Kahn-Denis 1997), through drama (Batson 1998, Casson 1994, Crimmens 1998, Wilkinson et al. 1989), and through music where much work has been done (Aldridge 1998, Bright 1988, Ishizuka 1998, McCloskey 1990, Prickett and Moore 1991, Threadgold 1995, Whitcomb 1994).

Creative writing with people with dementia is of particular interest, because like painting and sculpture, it gives the opportunity for the results in the form of poems or prose, or rhymes, to remain in a more permanent form than through the immediacy and embodied experience of movement and dance. This also means that they can be studied and appreciated more easily at a later date without being lost or forgotten. This does not imply that movement and dance work and embodied practices are any less important simply because they are difficult to capture or record, far from it, as it is still possible to film and analyse at a later date. I will reflect on some important examples in this section creating my own bridges of understanding in the process.

John Killick, writer and until recently Associate Research Fellow in Communication through the Arts at the University of Stirling, has pioneered the use of creative-writing in this field in the UK for the past nineteen years. His approach has been to work with individuals on a one to one basis, acting as a scribe for their thoughts and feelings and often as a craftsman in the way he pares language down to reveal the essence of the communication. He is most concerned that as readers of the poems,

‘we are therefore gaining insights into the states of mind and feelings of a hitherto largely unrepresented and neglected section of society’ (Killick, 1997b: 6). He describes a sense in which the exact authorship of the poems is sometimes, ‘a matter for dispute’ (p.7) and goes on to acknowledge his role in enabling the poems to happen. He also asserts that without his participation they would not have come into existence, which is important, because rather than the person with dementia writing poems for themselves, he is acting as a ‘go-between’; in part to enable their voice to be heard which would not otherwise have been possible and in part to enable expression of their unique lived experience. His understanding that the authorship of the poems is sometimes in dispute is also of interest. It arises, as I perceive it, in response to his working with people who because of the severity of their dementia may at times be unable or unwilling to commit their words to paper. Killick working as a scribe has to maintain the integrity within the form and content of the prose or poem. Interestingly, this parallels the fieldwork experience of the anthropologist where anthropologist and indigenous people are each trying to make sense of the other requiring insight, empathy, imagination, perceptivity and humility on both sides (Grau, 1999). I would argue that Killick here acting as scribe, together with the person with dementia, are both trying to make sense of each other using the same qualities of insight, empathy, imagination, perceptivity and humility.

There is a paragraph in Killick’s book ‘You are Words’ that is particularly revealing about his rationale:

A significant characteristic of the speech of many people with dementia is the direct expression of emotion. The disease has a dis-inhibiting effect and so the barrier to speaking directly of one's feelings has been swept away. At the same time intellectual capacities are diminished, and rational language proves elusive. Suddenly talk blooms with metaphor, allusion, the currents of feeling are reflected in rhythm and cadence. I have no doubt that the natural language of those with dementia is poetry (Killick, 1997b: 7).

This reference to 'metaphor, allusion and currents of feeling' that are reflected in cadence and rhythm within what Killick argues is the natural language of those with dementia is also important in underpinning my argument in this chapter. We need as care staff and therapists to be much more skilled at listening to and communicating with people who are giving expression to their 'lived' experience, to 'otherness' and 'difference' and doing so whether verbally or non-verbally. We must become more proficient at recognising **metaphor**, **allusion** and **currents of feeling** in our own practice, and ideas and techniques borrowed from anthropology can help us in that process. I recognise that in the care of people with dementia, creative writing offers unique opportunities to value the creative, expressive, sensuous and affective contributions of each individual, giving form and context to that expression and enabling Self and others to have a glimpse into the existential nature of their experience (often by way of the inter-subjective).

Kitwood speaks to the ways in which one might approach the person with dementia, drawing on his experience as a clinical psychologist and his psychotherapeutic understanding. He writes about the importance of first responding non-verbally to the person, to the non-verbal signs of distress or anxiety and of making an emotional contact where the verbal exchange is of secondary importance. After initial contact has been made:

We need to slow down our thought processes, to become inwardly quiet, and to have a kind of poetic awareness: that is, to look for the significance of metaphor and allusion rather than pursuing meaning with a relentless kind of tunnel vision (Kitwood, 1997a: 51).

Kitwood's reference here to a 'poetic awareness' is of central importance. Killick also is articulate about what he describes as the natural language of the person with dementia and a different kind of approach to listening that he has developed. He is, as a result able to make contact in sometimes very remarkable ways. The making contact is also about recognising the uniqueness of the person and valuing them by way of what they desire and are able to communicate. It is very existential, sensitive and important work and in my own practice and writing I would refer to Kitwood's having a 'poetic awareness' as similar to my own in developing a 'creative alertness' (Coaten, 2001: 21). We must as care-staff, artists and arts psychotherapists become more 'creatively alert' to the lived, embodied experience of the world of the person with dementia and creative-writing offers a unique way of working to that end. An example can be experienced in the following poem:

## **YOU ARE WORDS**

Life is a bit of a strain,  
in view of what is to come.

Sometimes I feel embarrassed  
talking to anybody, even you.  
You don't really like to burden  
other people with your problems.

I have been a strict person.  
What people and children do now  
is completely different. Any beauty  
or grace has been desecrated.  
The circle of life is shot away.

I want to thank you for listening.  
You see, you are words.  
Words can make or break you.  
Sometimes people don't listen,  
they give you words back,  
and they're all broken, patched up.

But will you permit me to say

that you have the stillness of silence,  
that listens, and lasts (Killick, 1997b: 10).

This remarkable poem was chosen as the title of his book. The poems themselves he regarded as being ‘vouchsafed’ to him by those with whom he worked. ‘Vouchsafed’ implies that they were not simply given, but rather the writer was *entrusted* with the task of getting to the heart of the intention behind the desire to communicate and finding a fit as closely as possible with what the person intended to communicate or as Ward has described it, ‘finding the best possible route to supporting their struggle to be heard’ (Ward et al, 2002b: 36). The poem both recognises and honours the essential qualities of personhood of the inspirer / co-creator of the poem, of the scribe and of the relationship between them. It also reflects for this particular individual the importance of listening and the importance of words and what Killick represented for this individual in the way that he was perceived as a ‘word-smith’ or someone who valued and loved words and somebody who was also able to listen. The words were what they shared together and had in common. Killick in the process will also verify that the words he uses and the form he gives to them are reflected back to the person, so that there is congruence between the creative intention of the person and its realisation by the scribe. The words can be changed, re-arranged or deleted if the person does not like or need them to be in that form. This is also an example of intersubjectivity and similar to the way the ethnographer traditionally tries to ensure accuracy in fact, context and representation by engaging in a similar process with their informants. It might also be argued, that far from seeking to make clear the nature of confusion as expressed through the condition, Killick is in fact leading

people to say these words and they are his rather than theirs. He does write in his introduction to the poems that all the ‘statements, questions and exclamations which fill these pages were compiled from transcripts of conversations with residents’ (Killick, 1997b: 7). I am confident that the process he used to create these poems held the person in high-regard, was not coercive in any way and has resulted in an extraordinary creative testament to the ‘lived’ experience and the world of the person with dementia. It also helps take forward understanding and knowledge about the ‘lived experience’ of dementia, which Kitwood and Bredin also struggled to come to terms with in their development of Person-Centred Care (Kitwood and Bredin, 1992c see Chapter 5).

Killick has through this creative act also helped reveal some unique characteristics about the individual concerned which may be of great importance in furthering the aims of the carer or care-staff in providing the highest levels of care. What has been revealed in the poem is the importance the individual attaches to being heard and understood, not just listened to. This is central to the meaning of the poem that is contained within the creative act of that individual. From an inter-subjective point of view if the meaning of the poem can be realisable for the care-staff, if they can feel and sense its full significance for the person, it could help create and realise important strategies for communication. These also might ensure that the individual is being properly heard and understood and that staff are more aware of how, and in what ways they can better communicate with the person to meet their needs.



An early draft of this chapter has been read by John Killick as my own 'informant', illustrating my on-going use of anthropological insights throughout this thesis. His comments were to the effect that I had accurately represented his work and approach in this chapter.

### **2.6.1 Subjective reflections - responding to the poem**

What follows is my own reflexive attempt to put myself in the shoes of the person with dementia who inspired 'You are Words', to attempt to get behind the words, the feelings in order to better understand the experience itself; a creative way to try and enter the inter-subjective territory of it. This response is taken from my own journal and these words were written in hindsight in the anthropological sense of a 'filed note':

'Probably a very private person he, not used to writing poetry or prose, or of having it written for him. Strict is the word. The pen did not glide effortlessly across the paper communicating deepest thoughts. John was there in the 'stillness of silence'. I am touched by this image. I think of stillness as the very heart of listening. My dance teacher, Mary Fulkerson got to the heart of this place too. She wrote:

One is available for imagined journeys which challenge, enrich and feed the working process. These things are all held as absences within the body. One waits as if empty through the whole process of this work and it is such availability that allows for the recognition of possibility.

This sense of absence is not passive. It has to do with the recognition of multiple possibilities (Fulkerson, 1977: 10).

I spent so many hours rolling on the floor in the studio doing contact / release work trying to find this 'waiting without expecting place' within me, that it left its legacy. As the writer says...the stillness of silence, that listens and lasts. The poem has a kind of legacy too, a momentary thing, a testament to a way of being, a way of relating, a way of listening and a way of being listened to. Like my dance training, it has a legacy that still feeds me now, being grateful for the seeds that were sown by my teachers and colleagues. Does one have to be a poet, a writer, dancer, artist or dramatist in order to be able to listen and synthesise or 'vouchsafe' in this way? Can a care worker do the same or similar? Can they not too learn and be open to new ways of being in the presence of mystery, of wonder, of personhood?

There is something vocational about this way of working, this way of being with the person that allows unique and heartfelt experiences to be explored and shared and sometimes transformed; the words pared down so there are none spare. There is something profoundly important too that carries me from one project to the next - and it isn't money, because there is no economic gain to be had from working in care homes that are often on the brink of extinction through lack of funds. In economic terms I earn very little for what I do in my practice. There are no spare

resources in homes for employing arts practitioners or arts therapists however well qualified. John K has been lucky to be financially supported in his remarkable work by a large, well-known provider of care. Perhaps a way can be found for carers to be involved in some properly funded pilot scheme that would give them training and experience in the creative arts?’

(Journal entry 14/12/01)

In using my own subjective experience through a journal response and writing quickly in a free associative way, I am able to bring to light aspects of the work I had not considered before. Kitwood was clear that, ' (i)f you want to explore the domain of subjectivity then use your own subjectivity to the fullest possible extent' (Kitwood, 1997b: 26). This was certainly what I was attempting to do here in the journal writing. Anthropologically the values, attitudes and beliefs held by the anthropologist, ethnographer or researcher/practitioner also influence the fieldwork experience and what is seen, noticed and reflected on. In relation to my own creative and subjective reflections on the poem I have been able to make a link between the phrase, ‘you have the stillness of silence, that listens, and lasts’, and my own training in dance and movement. This triggered a link with my own teacher Fulkerson and my experience of her work and how that continues to inform and develop my practice. It is interesting and important to me that by trusting in a creative process and working reflexively, subjectively and inter-subjectively, without rushing to know or understand, new insights and understanding have emerged naturally without being forced or people knowingly coerced. Care staff should be given access to the creative

and performing arts, creative writing and movement and dance in particular because they are about making something special. Creative writing and poetry is able to give expression to people for whom there may be no other way to express their own uniqueness or their own process of 'making special'. Dissanayake (Dissanayake, 1995: 59) argues that, 'making special emphasizes the idea that the arts, biologically endowed predispositions, have been physically, sensuously, and emotionally satisfying and pleasurable to humans'. I like this idea that 'making special' is biologically programmed into us and that it is both 'deep-seated and widespread' (op.cit.: 60). If there is already a biological predisposition to 'making special', then could this be validation for building on it by creating a culture of care that could be described as 'Creative Care'? This would mean one that is more biologically predisposed, sensuously oriented, encouraging self-expression and communication in a variety of different and uniquely individual ways; which could also make a major contribution in improving the quality of care services. I will discuss this idea further in Chapter 8 (see section 8.3).

## **2.7 Reflexivity in practice and research**

I am struck by reading Hanna:

The essence of an anthropological approach is to understand the culture of the individuals with whom one interacts. Culture is a dynamic ever-changing phenomenon encompassing the values, beliefs, attitudes, and learned behaviour shared by a group. Anthropologists seek to understand the meaning of the webs of significance humans spin from their

perspectives. Within this vantage it is necessary to understand how individual clients, as well as the cultures to which they belong, define a problem, view its cause, and evaluate the progress of its resolution (Hanna, 1990: 116).

I can relate to this image of anthropologists seeking to understand ‘the meaning of the webs of significance’, and I like the image of a web, each thread connecting to the other and making a coherent whole. Sometimes the coherence of the metaphoric ‘thread’ cannot be perceived in its entirety as in trying to fully understand the significance in the rhyme reported by Doris Sarah Loxley, referred to earlier (see Section 2.5). We can wonder at where in her life experience this story is rooted and remain in its presence seeking for more insight into its meaning and relevance. I can relate to this image in working with people for whom it is often very difficult to define the problems they are experiencing, let alone the causes and the progress of their resolution, whether as dance movement psychotherapist or member of a multi-disciplinary care team. I am aware that dementia syndrome and its effects are both irreversible and progressive resulting in a loss of many skills and abilities. During group sessions, however, there are facts, information, stories and rhymes (Doris) the care staff may not have known about, prior to our time spent together in DMP. These threads of memory and communication are, I believe, crucially important in being perceived and felt in a wide variety of ways. Once they have been located and experienced they need to be synthesised in relation to their usefulness and potential application in the care setting.

Many care staff interviewed by Ward et al (2006a) spoke of the tension between the kind of care that they would ideally like to be able to provide and the kind they felt compelled to give. There were many pressures and differing demands on their time that Kitwood too has clearly articulated leaving little time for one-to-one communication or getting to know the older person and the older person getting to know them. It might also be the case that care staff, in spite of poor training and little academic ability, do naturally and inherently possess the skills and abilities to pick up on the many verbal and non-verbal communicative cues that people with dementia give. Ward et al (2006a) argue that this is indeed the case, with communication taking place often without a framework, a common language and un-supported by any staff training. This results in care staff not being able to communicate, let alone synthesise, sophisticated non-verbal communication so that they and their colleagues can meet older people's needs, even if they possess the skills and abilities to do so. This is like a sophisticated and fine web of connections and inter-connections, with care-staff and people with dementia each responding to the other within a formal care context, each potentially changed by that experience and some more than others.

Care staff have to, without exception, reach out to find those webs of significance that make the difference between a mediocre, task-oriented type of care and what might be described as 'Creative Care' or an approach to care that acknowledges the uniqueness and embodied relational nature of every person demanding a uniqueness of approach.

The image of 'webs of significance' is important in working with people with dementia, as often all that is left are threads of memory, fragments of story, sometimes jumbled words and mumbled sounds that could be described as seemingly insignificant and not worthy of our attention. Close relatives and carers who have known and loved the person can make sense of the communication far more accurately and quickly than a care worker meeting the person for the first time; because they were a part of the creation and maintenance of that familial web in the first place. A care worker much younger than the older person, unused to the particular accent, tone or inflection, of a resident's felt act of communication or even of their life story, has to work hard to pick up the significance of what is being communicated. They also have to do this within the complexity of the nature of that communication, given that communication, '...is interactive, residing in dialectic relations between form and content, stream and information, code and message, culture and behaviour, production and reception, construction and interpretation' (Feld and Keil, 1994: 78). In getting it wrong by not hearing, seeing, feeling or intuiting the communication in the way it was intended and making sense of it, the care worker risks not being able to meet the needs of the person at that time with the resulting negative impacts on the person as reported by Gibson (1999), Goldsmith (1996), Killick (1997a), Kitwood (1997a) and Ward et al. (2006b). Finding sensory anthropological approaches and methods, including arts based ones that support communication with people for whom it is difficult can become an important part of providing high quality care.

## **2.8 The importance of meaning in working with people with challenging behaviours**

In a series of important studies with people with dementia regarded as vocally disruptive, Hallberg reported that much disruptive vocalisation is an attempt to communicate with self and others and that carers were likely to view such communication as meaningless (Hallberg et al, 1990). In later studies they went on to suggest that the emotions being expressed were indeed meaningful and important and related to an increase or decrease in negative feelings (op.cit.: 1993). In other words disruptive, vocalisations such as screaming, yelling or shouting are far from being meaningless and simply a part of the condition; they are an important indicator of distress and serious observed ill-being, as defined within the meaning and context of person-centred care practice. My first response is to intuit what might be causing the distress; I may also consult with colleagues. Often there is a need to work hard using intuition and imagination and as Dance Movement Psychotherapist reading the body-language of the distressed person. A calming voice, a re-assuring hand, empathy, insight and understanding can help calm the person and then one works verbally and non-verbally toward finding meaning in those webs of significance and identifying what might have caused the distress. Once this has been accomplished (if possible) then it is necessary to learn from the experience and pass on any of the learning to one's colleagues in the multi-disciplinary care team and where appropriate to the family. This should result in increased well-being and a subsequent reduction in what have been described as challenging behaviours (Cohen-Mansfield, Marx and Rosenthal, 1989, Cohen-Mansfield, Werner and Marx, 1990).



## **2.9 The value of anthropological insight and understanding in the work setting**

This chapter has referred to a number of key concepts taken from anthropological and ethnographic literature that I argue as important and useful to my own development as a more reflexive and able practitioner/researcher. They are also relevant to a wider audience within the field of dementia care research and practice in helping broaden and deepen the thinking about what it means to have a dementing illness and how best to respond as a result. I have provided specific examples where I have tried to build bridges of understanding between difficult and complex human interactions and situations ('Martin' and 'Doris') and where I have used specific ethnographic techniques ('scratch note' and 'field note' and 'filed note') in improving my practice. The remaining sections of this chapter present a number of useful avenues where these insights and understandings are of particular relevance in the care setting.

We can better appreciate the inner world of the person with dementia if we are better able to understand the different verbal and non-verbal cues they use in order to relate to and communicate with the world and those around them. It also helps as far as possible to know their life history. Recent research has highlighted that the development of skills and the potential for improving expertise in affective communication remains 'submerged and unsupported in dementia care settings' (Ward et al, 2006b: 24) and this is both a challenge to us as care practitioners and an important area for development. Downs et al. (cited in Bruce et al, 2002: 337) also draw attention to the fact that care-staff have only a partial acceptance that meeting emotional needs is a part of their job. Improving affective or emotional

communication is a big challenge and means at an individual level paying closer attention to the language and the words people use and the opportunities presented by way of improving relationships between those being cared for and those doing the caring. It means at an organisational level that settings and their managers are better prepared to accept this as a priority within the context of their own training plans and to fund and meet identified staff training needs, through high-quality leadership and training programmes. At national level it means a recognition that the training and development of care-staff in dementia-care must also be given a higher priority, given the increasing numbers of people predicted to suffer from the disease in future years (I shall discuss this in some detail in Chapter 3 (see section 3.2). This is beginning to happen in early 2009 in relation to publication by the Department of Health of the National Dementia Strategy (Dept. of Health, 2009) and its intention to improve the quality of care at a national and strategic level in England, Wales and Northern Ireland.

I argued above that creative writing for the person with dementia plays an important role in providing a uniquely important mode of expression that can give form and context to emotional and affective communication for the person, and inter-subjectively enable those creative acts to be converted into practical ways and means for improving their care.

One of the most important lessons anthropology can pass on to dementia care practitioners in the work setting is how and why ‘difference’ and ‘otherness’ is not something to be afraid of, or resistant to, but a feature to embrace as eagerly and

naturally as those early anthropologists embraced the indigenous peoples they were studying. I appreciate that for the average care worker this is going to be difficult, but central to better understanding ‘otherness’, is language and language expressed in a multiplicity of ways. By this I mean that care-staff are able to accept the images, the sounds, movements, behaviours and language of the person with dementia not as inconsequential and meaningless but as potentially *full of meaning* and constantly expressed differently by every person. I would argue that dementia transforms experience just as much as it transforms the personality of the person experiencing it. We can best help the person with dementia if we are like anthropologists and ethnographers, seeking at all times to better understand the world of the person with dementia and how that is expressed in and through the culture (dementia care setting) and the language. This means in particular:

- Listening and paying much more attention to the ‘lived experience’ of the person with dementia through the sensory, sensual, gustatory, affective, aural and embodied worlds which they inhabit.
- Listening much more intently and perceptively to the stories, narratives and rhymes people tell about themselves and others and about their lives (e.g. Doris).
- Becoming much more aware of and attuned to metaphor, allusion, symbolism and ‘currents of feeling’, making better sense of these as far as possible.
- Developing and using more non-verbal body based approaches/embodied practices through DMP and body psychotherapies.

- Using creative writing and other arts based creative practices to provide emotional and affective expression.
- Sharing these insights and understandings on a regular basis with colleagues and carers aiming to improve care practice by way of improving relationships in the care setting.

In a real sense, the world of the person with dementia is being turned inside out through all the debilitating changes taking place. I would argue that in response the care-staff or carer must be prepared to find ways to meet the person in this potentially very different, 'other' place in order to reach the person in the condition; to appreciate and learn the language that is most appropriate for reaching the person with dementia. Care staff and carers better able to tune in to the person in such a way that they can hear with new ears and see with new eyes. Senses are tuned to wavelengths that within the context of an 'anthropology of the senses', can be expressed as a gustatory awareness (Stoller, 1989), an acoustic or vocal awareness (Feld, 1996, cited in Ravetz, 2001), 'a poetic awareness' (Kitwood, 1997a), 'creative alertness' (Coaten, 2000) that finds the images, the sounds, the poetry behind the words as important and meaningful; necessary in the work setting to creating a more enlightened, human and sensory-oriented care culture.

## **2.10 Concluding thoughts**

Some contemporary anthropological texts refer to metaphors, poetic imagery, such as 'building a bridge of understanding' and 'webs of significance', landscapes of sound,

gustatory understandings and they call for an increase in reflexivity, subjectivity and inter-subjectivity. I find the poetic, the sensory, the metaphoric, symbolic and embodied practices very helpful in my own work enabling me as a Dance Movement Psychotherapist to be carried deeper into the 'Being' of the other. This concept of 'Being' in relation to dementia care is of great importance in current dementia practice and will be discussed and expanded in more detail in Chapter 5 (Sheard, 2008a). I also understand anthropology to be a discipline that attempts to see how people construct their world and to better understand how others understand. What if the poetic, the visual, the musical, the embodied and kinaesthetic senses can be experienced as more encompassing and accessible to the person with dementia enabling them to make more sense of their own condition and others to do so as well? Could they contribute to improving the quality of care for a person with dementia who has to leave their home and be cared for by professionals in a completely different and potentially alien setting? I believe that they could and I have argued in this chapter that contemporary ethnography and anthropology with their specific approaches and techniques offer valuable theoretical and practical tools in supporting this aim; and in helping understand the world and experience of the person with dementia and those who care for them. I say this with a sense of urgency and awareness having reflected on the statistics (to be discussed in Chapter 3, section 3.2) and the facts, evidencing that:

It has been estimated that the cost of dementia care exceeds that of cancer, heart disease and stroke combined. Given our ageing population, this is a challenge

that will only grow in size, with the number of people with dementia projected to double in the next thirty years (Dept. of Health, 2008: 3).

The challenges presented to all those currently living with and caring for people with dementia demand greater attention being paid to this neglected area of study and need and new ways found to work more effectively, more creatively and more humanly. I conclude this chapter with a final poem taken from the Professor Kitwood Memorial Poetry Competition 2002 that for me makes extra-ordinary cross-cultural comparisons, inter-generational reflections and a comment on the ease with which a child is able to make sense of the embodied experience of an older person with dementia. It was written by a woman, Salli Blackford, 'inspired by watching a shared moment between my mother and my grandson'. It is for me touching, sensory and embodied going to the heart of a child-like way of listening, paying attention and being inter-subjectively in relationship with. It also goes to the heart of how we may all need to learn to touch and make contact with people with dementia – in both extra-ordinary and utterly ordinary ways; in which profoundly human and important processes of listening and paying attention will help reveal purportedly lost memories, skills and abilities transforming both organisations and individuals alike. We have much to learn from the insight and natural wisdom present in the ability of the child to listen, hear, sense, intuit and make sense of that for which an adult often has to struggle.

## **His Hand in Yours**

He gently grasped your hand

With his tiny fingers

and led you

To a seat.

He gave you a toy

And watched your face

Your eyes

You smiled

You turned the toy over and over

Making sense of it.

He understood

He does this too

To make sense of it

There is no sense

No way, as adults

That we can understand

But a two year old knows

He sensed your space

He understood your sounds

Your walk

Your constant search

Your fingers in the custard

He understood

He does this too

To make sense of it.

He rested against you

He knew his great-grandmother

The world sometimes puzzles him

He understood

For a moment

You both made sense of it.

(Blackford S, 2002: 4)



## **Chapter 3**

### **Understanding Dementia Syndrome from different perspectives**

#### **3.1 Introduction**

This chapter sets out to discuss and analyse several different conceptual and epistemological frameworks for how the term ‘dementia syndrome’ is understood and defined within the dementia care community. Dementia syndrome can be studied from a number of different perspectives: no single framework or body of knowledge can supply all the answers. Each looks from a different angle, through a different ‘lens’, and sees different aspects of the syndrome in consequence. Each viewpoint also has differing strengths and weaknesses, in relation to what is and what is not seen and considered of consequence. Firstly I have chosen to discuss the Bio-medical framework, which predominates in the NHS and is a key perspective in understanding dementia. The Psycho-Social perspective follows the Bio-medical and represents a very different, yet equally important world-view. The chapter then proposes a new ‘embodied’ framework for understanding the syndrome, arguing that there is currently an important gap in the knowledge and skills base. It is new work, aiming to conceptualise dementia syndrome from the perspective of the ‘lived body’. Importantly, this ‘embodied’ framework provides a place for Dance Movement Psychotherapy (DMP) to be better understood in relation to other epistemological frameworks presented here. I aim to open up new thinking regarding the use and importance of ‘embodied’ practices in conjunction with other approaches to

understanding dementia syndrome. The concluding section discusses other problems in relation to the treatment and care of people with dementia.

### **3.2 Dementia Syndrome – a bio-medical perspective**

Within a bio-medical perspective, dementia syndrome is understood as being a clinical syndrome, a generic term associated with a number of disorders rather than any specific one. The syndrome is 'characterised by a widespread loss of mental function, with the following features: memory loss, language impairment, disorientation, change in personality, self-neglect and behaviour which is out of character' (Dept. of Health, 2001a: 96).

The dementias have a number of causes and can be 'fixed', as in the case of someone with a head-injury, or 'progressive' and 'degenerative', as in Alzheimer's Type Dementia (ATD). ATD is also irreversible, while others might be reversible as in the case of damage caused by an operable tumour. The degenerative dementias are most common in the general population, and of these the two most notable are ATD and Vascular Type Dementia (VTD). ATD is characterised by progressive memory loss and difficulties with language in the early stages, usually without any remission. In contrast, with VTD 'there is a history of transient ischaemic attacks, fleeting pareses, or visual loss. The dementia may also follow a succession of acute cerebrovascular accidents or, less commonly, a single major stroke; some impairment of memory and thinking then becomes apparent' (World Health Organisation, 1992: 50). With VTD it is more likely that remission from symptoms will occur, meaning that people can vary in their behaviour, their affect, their language, mental and physical functioning

including activities of daily living. Remission can be seen, for example, in short-term memory, in mood, in ability to communicate followed notably by further deterioration. Of equal significance is the fact that ATD and VTD can co-exist, making the process of assessment and diagnosis particularly challenging for medical practitioners.

Bio-medical research is focused on two main areas: identifying the causes and risk factors involved, thus helping to prevent the disease, together with understanding the process or pathology in order to develop better drug treatments. Research into the demographics of the degenerative dementias has advanced rapidly. In 2001, it was thought that ATD caused up to 60% of cases of dementia in the United Kingdom alone, with VTD prevalent in about 20% of cases. Dementia with Lewy Bodies was responsible for a further 10% of cases including Parkinson's Disease dementia, while the other dementias including alcohol related (Korsakov's syndrome) and Pick's Disease took up the remaining 10% (Dept. of Health, 2001a).

In 2005, the statistics and thinking changed according to research in the field, indicating a less clear-cut and more complicated picture in the differential bio-medical diagnosis of dementia. Interestingly, the global picture related to the range and quality of approaches used and services offered has also grown more rich and complex over this time. For example, ATD and VTD are coming to be referred to as 'Proteinopathies' and 'Vasculopathies' respectively. Proteinopathies are characterised by the build-up in the brain of three main types of protein: Beta-Amyloid, Alpha Synuclein and Tau, with the resulting loss of neuronal function and brain activity

where these protein deposits are located. Each proteinopathy type tends to target specific regional cell areas in the brain causing cell loss in that area (Bayer, 2005). For example, Beta-Amyloid 42 is associated with the hippocampus, temporal and parietal neocortex and frontal lobe, causing the neuro-fibrillary 'plaques and tangles' as reported by Alois Alzheimer (Alzheimer 1911, cited in Graeber et al, 1997). Vasculopathies on the other hand, are associated with the blood flow and vascular type dementias. The demographics have also changed since 2001. In 2005, for example, ATD on its own was associated with only 40% of people rather than 60%, vascular dementias and ATD (co-existing) with 20%, VTD on its own (Multi-infarct and Binswanger's disease) only 10%, ATD and Lewy Body dementia 10%, dementia with Lewy Bodies and Parkinson's type dementia 10% and other dementias including Frontal Lobe, Creutzfeldt-Jakob also 10% (Bayer, 2005). These changes in the demographics of dementia in the UK, based on the 2005 figures, reflected a greater complexity and detail about what was becoming better known about the syndrome from a bio-medical perspective.

The evidence presented above represented a considerable overlap between the proteinopathies and the vasculopathies. In 2001, Snowden referred to several autopsy studies carried out by Markesbery, a research pathologist, on Kentucky men and women (Snowdon, 2001). These identified that in 2000 vascular dementia on its own was relatively rare.

Evidence also suggested the incidence and prevalence of dementia increases with age, and in 2001 there were approximately 600,000 people with dementia in the United

Kingdom. This represented 5% of the total population aged 65 and over, rising to 20% of the population aged 80 and over. Dementia can also occur before the age of 65: in 2001 there were about 17,000 people in the younger age groups. Of great statistical significance was the estimate of 840,000 people with dementia in the United Kingdom by 2026, rising to 1.2 million by 2050 (Dept. of Health, 2001a). According to the most recent figures (Alzheimers Society, 2006/7), in 2007 there were 700,000 people in the UK with dementia, with numbers currently projected to soar to 1.7 million by 2050, which is a considerable all-round increase on projections made in 2001 (see above).

The statistics alone indicate that this is an increasingly significant medical, social, economic and familial problem for society, with costs to the State running at £17 billion each year (Alzheimers Society, 2006/7). A recent editorial in the Journal of Dementia Care draws on these figures and criticises the current government for lack of attention to these matters:

Dementia care is severely underfunded and as the pressure increases from an ageing British population the challenge could not be greater...(h)owever time is not on our side: with an almost exponential increase expected in the numbers of people living with dementia, this planning needs to start today (Hunt, 2008: 9).

I would agree with the comments made here, highlighting a severe neglect of funding coupled with the fact that individuals and their families are coping with the effects of the disease *in ever increasing numbers*, compounding the burden on those who care

for them. Indeed the burden on the person with dementia and their carers is fast becoming a significant area of concern and study for current and future researchers. Major funding bodies such as the Mental Health Foundation, are developing initiatives such as the 'Home Improvements Programme' as reported in the Journal of Dementia Care (Benson, 2008: 8), which are at last aimed at improving the quality of care in residential homes at a national and strategic level.

Also from a bio-medical perspective, behavioural disturbances associated with dementia (Cohen-Mansfield et al, 1989 and 1990) can substantially impair the quality of life and the ability of families and care staff to manage them (Moniz-Cook, 1998). It is increasingly recognised bio-medically that psychotropic drugs used to treat challenging behaviours can have serious side-effects (McGrath and Jackson, 1996, Thacker and Jones, 1997). For example, mortality can increase up to six-fold because of sensitivity to drugs, leading to an increased risk of strokes (McShane et al, 1996).

From a bio-medical perspective, the proteinopathies or vasculopathies are very difficult to diagnose accurately, even with high quality scanning equipment. They are described as being diseases associated with 'insidious onset', meaning that it is not possible to define accurately the date or onset of the disease. Unlike other diseases, dementia syndrome according to Snowdon has an incubation period of somewhere in the region of twenty years to become fully noticeable, and not simply part of ordinary forgetfulness and in most cases the only reliable way of confirming a diagnosis is through brain autopsy after death (Snowdon, 2001).

Having reflected on bio-medical perspectives in relation to dementia syndrome in general, it is necessary to consider in some detail their epistemology and their on-going effects on the care environment. The origin and value base of bio-medical science is rooted in scientific knowledge and this means that some types of knowledge will have preference over others. For example, within the bio-medical epistemology 'knowledge that matters is impersonal, public, productive and empirically verifiable; knowledge that is personal, tacit, experiential or intuitive is hardly recognised as knowledge' (McWhirter, 1995 cited in Hill, 2004: 224). Bio-medical science according to Hill (2004) and Kitwood (1997a) has had a significant impact on holding back the development of person-centred care practices. Kitwood, a pioneer in the field, argued that the impact of bio-medical science on the development of person-centred care practices was a problematic inheritance (Kitwood, 1997a). Developments in medical science have brought benefits to the treatment of the person with dementia, including much improved diagnosis: 'we are beginning to understand the neurophysiological and neuropathological substrates of mental processes; there are now treatments that can bring rapid relief from some very distressing symptoms' (Kitwood, 1997a: 43). However, while there are positive and important on-going developments, in relation to a bio-medical assessment of cause, cure and care, the underlying values of those trained in bio-medical science, including doctors, psychiatrists and nurses, remain a big problem. For example, in care systems both here in the United Kingdom and Australia (the location of Hill's study), there is still a prevailing over-emphasis on pathology and treatment of the person as object, 'Medicine focusses on the object body of science' (Twigg, 2006: 71), without sufficient attention paid to the psycho-social and embodied aspects of care. Nettleton

(1995, cited in Hill, 2004) has referred to five assumptions underlying the medical model each of which has produced subtle negative effects on the care environment. The first is the Cartesian ‘mind/body dualism’ which since the Enlightenment of the eighteenth century has placed an emphasis on cognition to the detriment of embodied forms of knowing and mind/body unity. The second is ‘mechanical metaphor’, that is, the idea that the body can be repaired and understood like a machine. The ‘technological imperative’ describes an over-emphasis and reliance on technology; ‘reductionist’ explanations of the disease model emphasise the biological over the psycho-social, environmental and humanistic, and lastly the ‘doctrine of specific aetiology’ refers to the Germ Theory of disease which arrived at the end of the nineteenth century, as caused by specific named pathologies. These five assumptions are built into the bio-medical training of doctors, psychiatrists, psychologists and nurses. Here in this excerpt from his poem, ‘The Love Song of J Alfred Prufrock’, Eliot captures the essence of the ‘mechanical metaphor’, the ‘formulation’, referring to the ‘reductionist’ approach and the glaring failure for the person in the poem to be seen and recognised as they are:

And I have known the eyes already, known them all-  
The eyes that fix you in a formulated phrase,  
And when I am formulated, sprawling on a pin,  
When I am pinned and wriggling on the wall,  
Then how should I begin  
To spit out the butt-ends of my days and ways?  
And how should I presume? (Eliot, 1917: 40)



This poetic and ‘embodied’ image of ‘sprawling’ on the end of a pin, like a butterfly about to be fixed forever, caught as yet another object in the butterfly collector’s case, is a powerful one. Also implicit in the poem is the rather desperate plea the person makes, that they should be seen, heard and understood in their totality, rather than ‘formulated’, or reduced to some formulaic construct where pathology is paramount, life-story irrelevant. Eliot, in this extract, gets poetically to the heart of a fundamental problem and by-product of medical science. The individual nature of the patient becomes left behind in their treatment, as their condition, as understood over a considerable period of time is framed as physiological process or pathology, seen and measured by the scientific method (Twigg, 2006). While the pathology or medical problem has to be diagnosed and labelled, the predominantly empirical and ‘reductionist’ way of going about it often ignores the psycho-social aspects, and other difficult to measure features of the person’s presentation, including life-story, identity, environmental, gender, race and cultural issues. These processes began in the mid-eighteenth century and have gathered momentum ever since. Momentum has increased up to the present day in response to developments in anatomy and dissection, the discovery of the Stethoscope, X-Ray technology and other more sophisticated examination techniques (Twigg, 2006).

The study of mental health by psychiatry in the bio-medically based treatment of people living with dementia has also developed over time, and it is necessary to give a brief, contemporary and clear definition of psychiatry before proceeding. Psychiatry is understood as ‘the branch of medicine concerned with the study and treatment of

mental illness and emotional disturbance' (Soanes and Hawker, 2005) and typically involves assessment, mental status examinations and the taking of a case history. Old age or geriatric psychiatry as it is known, is the specialist area of study, research and medicine involving people over the age of sixty-five. In better understanding the bio-medical aspects of dementia modern assessment tools are used such as Magnetic Resonance Imaging. Psychiatrists must also have studied the biological and social sciences in the diagnosis, treatment and management of people with dementia.

### **3.3 Dementia Syndrome - a psycho-social perspective**

This is only a short section on the psycho-social as in effect the whole argument of this thesis is fundamentally psycho-socially oriented, with a major slant towards the embodied and lived experience of people experiencing the condition and those caring for them.

In attempting to better understand dementia syndrome in relation to its impact on the person living with dementia and on those who care for them, it is necessary to think about its aetiology from a psycho-social perspective that exists alongside a bio-medical one. A bio-medical perspective results in symptoms seen very much in relation to the disease and its presentation in the individual, whilst the unique relational characteristics of the individual's response may remain largely ignored or not given sufficient consideration. A 'psycho-social' perspective means acceptance of the social, the psychological and environmental aspects all of which have their effects on the individual that need equal consideration. I consider the psycho-social of equal importance to the bio-medical perspective that conceptualises the person first and the

dementia condition second; the psycho-social grounded in a more embodied and lived reality than the more linear and cognitively oriented bio-medical. Both however need to be properly considered in any comprehensive and high-quality care and treatment work, by way of understanding that the dementia condition takes its course within what Kitwood has described as a ‘dialectic’ of key factors impacting on the person and their environment and not simply their pathology as bio-medically conceptualised (Kitwood, 1997a). Kitwood has succinctly exemplified this understanding in a helpful way by arguing that it is not the, ‘person-with-DEMENTIA’ (Kitwood, 1997a: 7) that counts in his thesis, so much as the ‘PERSON-with-dementia’ (op.cit.:7). I like this very brief and clear summary, which I currently use in staff training and development programmes on the subject of Person-Centred Care.

If the psycho-social or the psychology of relationships is left out of the equation in trying to understand dementia syndrome better and its impact on people, then there is no place for the context and environment, social and psychological within which the dementing condition plays out. There is no place, in other words, for giving people with dementia a sense that in spite of their condition there is much that can still be accomplished, socially, psychologically and environmentally, to enable them to cope better with the condition. In other words to continue to use as many of the individual resources that remain relatively unaffected; and to put them more in control, living lives as full and rich as possible. There is, for example, within this psycho-social paradigm the presence of *hope*; the on-going possibility that in spite of every eventuality they are still human beings and can still make sense of their world as best they are able. They still have the wherewithal to banish the shame and the fear that is

so much a part of the condition, particularly in relation to how it is perceived generally in society. It is within this new paradigm that DMP finds a culture and values that understand, support and encourage its development. I am confident therefore that DMP, will over time, become increasingly accepted as a valuable contributor to the changing culture of dementia care from both a psychological and a psycho-social perspective.

Lastly, in this section, one of the most effective arguments in support of the psycho-social perspective concerns the fact that dementia syndrome does not follow a straightforward linear progression (Kitwood, 1997a). It is no longer theoretically or clinically possible to conceive of within the standard bio-medical paradigm that Kitwood equates to a 'billiard-cue' (op.cit.: 35) idea. The cue, metaphorically speaking, sets a 'ball' (or genetic anomaly) in motion, which sets another going and so on and so forth. The reality of causation is far more complex, more quantum and for the scientific community particularly challenging as they are today no closer to understanding the causes of dementia syndrome, even if they are making progress with a passive vaccine and other pharmaceutically oriented treatments (Bradley, 2009). Also on the subject of aetiology it is not possible to equate the numbers and distribution of the plaques and tangles of a proteinopathy with resulting changes in behaviour, affect and communication, or other cognitive losses. Snowdon (2001) in detailed and thorough work during post-mortems on the brains of nuns, in the Nun Study in the United States, discovered that there is no co-relation between a person having the highest number of plaques and tangles on the Braque Scale and their functioning being logically found to be very impaired indeed. In fact the opposite was

true, people with a very high Braque Scale score of 5 (post-mortem) had functioned in everyday life as would have been expected in someone with a very low score; vice versa people with a low Braque Scale score had been found to be very impaired indeed in activities of daily living. The reality is that each person will experience the condition in their own way presenting the problems concerning diagnosis, treatment and care as fundamentally existential. Consequently a very broad range of skills and perspectives in diagnosis, treatment and care are called for, and this argument is theoretically supported by the work of Best (2003) as discussed later in this Chapter (see section 3.5). The traditional understanding of disease pathology within the biomedical model is that strong and linear correlates will always be found between disease pathology and outcome. People with a dementing condition however defy this traditionally understood connection in the disease model. The assumed links between brain structure and function in ATD and VTD have been found *not* to apply as a result of the work of Snowden (2001) and as reported and discussed by Kitwood (1997a). They do not follow the standard linear model and this has led some to describe the traditional disease model as a ‘paradigm in disarray’ (Kitwood, 1997a: 34). Kitwood goes on to call for a much better description of what he describes as ‘a set of interacting conditions – all necessary but none sufficient in themselves – that are required for an event to occur’ (op.cit.: 36). In order to move knowledge and understanding forward in this vitally important area of science, both generalised theory and great attention to individual specificity are going to be needed.

### **3.4 Dementia Syndrome - an embodied perspective.**

Constructing, embracing and enabling an ‘embodied’ approach to conceptualising dementia should make it easier for researchers, clinicians, Dance Movement Psychotherapists and others in the field, to know that ‘embodied’, predominantly non-verbal practices have a sound epistemological base. This is not to design a new conceptual framework per se, rather to draw on an existing sensory, experiential, academic and clinical knowledge base linking to the work of Abram (1996), Bloom (2006), Coaten (2008), Csordas (1988), Hill, 2004, Merleau-Ponty (1962), Kontos, (2005, 2009), Palo-Bengtsson, (1998a, 1998b), Phinney and Chesla, (2003), Sacks (2008). A sound epistemological base requires the creation of a language/vocabulary to describe in detail what these ‘embodied practices’ mean in the context of care and clinical practice. Developing that language/vocabulary to contextualise, systematise and clarify the nature of these embodied ways of working that can then be properly understood and disseminated in the dementia care field is not the purpose of this thesis. It does attempt however to investigate in detail some of the phenomena that undoubtedly contribute to it, so it is headed, metaphorically speaking, in that general direction, which others can build on in the future.

‘Embodied practices’ mean being able to engage and relate through the lived experience of inhabiting a body and thus being in relationship to self, others and the world. To ‘embody’ means to have or hold something within the body in any number of ways e.g. metaphorically, physically, psychologically, emotionally, spiritually etc; in effect to live that something through relationship with one’s body. This definition assumes two things: first that we have a body in which we exist in the world, and second that we have access to the world through the body in which we experience it.

Merleau-Ponty (1962) was a philosopher and academic who took the body and its impact on perception seriously. He challenged previously held notions that essentially embodied forms of knowing and experience were subservient to the powers of cognition and intellect and could be ignored or disregarded in the phenomenology of perception. Cognition and intellect were seen at the time in the 1960s as the key dimensions in the phenomenology of perception (Merleau-Ponty, 1962). This was to the denigration of other dimensions of knowing including emotion, spirituality and humour. In his early researches he referred to “le corps-sujet”, the ‘body subject’, where he built on Husserl’s earlier research. Indeed, according to Abram, he set out to, ‘radicalize Husserl’s phenomenology, both by clarifying the inconsistencies lodged in this philosophy by Husserl’s own ambivalences’ (Abram, 2006: 44) and by using words that attempted to embody and communicate this reality as Merleau-Ponty (1962) saw it. He re-framed the importance of the lived body in a completely new way and addressed the duality of the Cartesian mind/body split, by arguing in effect that it was a delusion, or what Abram (1996) has called a ‘mirage’:

The common notion of the experiencing self, or mind, as an immaterial phantom ultimately independent of the body can only be a mirage: Merleau-Ponty invites us to recognize at the heart of even our most abstract cogitations, the sensuous and sentient life of the body itself (Abram, 1996: 45).

As the body is the medium that alone enables us to be in relationship to the world and all phenomena in it, then without the body there would be no possibility of experiencing the world. This logically presupposes that the body in and of itself is the true subject of experience. Merleau-Ponty was not the only philosopher pioneering embodied practices in the 1960s and writing eloquently about it;

The discovery that the body has a life of its own and the capacity to heal itself is a revelation of hope. The realization that the body has its own wisdom and logic inspires a new respect for the instinctive forces of nature (Lowen, 2005: 217).

Lowen, one of the pioneers of ‘Body-work’ and ‘Bioenergetics’, here refers to the development of body-based knowledge and wisdom that is congruent with the ideas and theories of Merleau-Ponty expressed here in this section.

Earlier in the 1950s, Rudolf Laban had described the body as ‘the instrument through which man communicates and expresses himself’ (Laban, 1980: 50). Laban also perceived in the process the essential relationship between our embodied moving selves and the physical world. Following his pioneering ‘time and motion’ studies in factories in Germany before the Second World War, he and others went on to create a detailed and sophisticated framework for notating and analysing movement, in the form of what is now known as Laban Movement Analysis (LMA) (Lamb and Watson, 1979, North, 1972, Kestenberg and Sossin, 1979, Bartenieff and Lewis, 1980). LMA has since been adopted by the DMP community to support their practices and indeed in the UK and the USA is an essential analytical tool of DMP.



Contemporary researchers in the last five years in the dementia field have also referred to the body in the dementia literature as the ‘lived body’ (Dekkers in Purtilo et al, 2004, Phinney and Chesla, 2003, Kontos, 2005). The lived body is the body that is immediately apparent to me as I live and experience it. All that I sense, feel, touch, taste for myself is experienced, expressed, lived and mediated through this, my body. Merleau-Ponty also proposed the idea that the lived body possessed its own knowledge of the world, what he called a “tacit knowledge”, and that this knowledge functioned outside of our conscious control. This knowledge is not based on cognition or cognitive processes but is inherent in our having a body and being human. In relation to my own movement and dance training and my subsequent movement based experiences in relation to the lived body, I have referred to what I described as an inner kind of intelligence and sensitivity:

Working from the intelligence of the body is about a process, not an outcome, which creates a spontaneous flow of information that is very different from intellectual information...the voice of the body rises when the intellect moves over. It doesn’t offer diagnosis, treatment or cure, but contributes to an enriched awareness and understanding about how dis-ease manifests in and through the body. Insights occur through the movement itself, or through reflection and discussion following movement, and these can contribute to a greater understanding of what might be going on within oneself (Coaten R, 2000: 114).

References here to process, greater awareness, intelligence and understanding in relation to the lived body are central to what embodied practices mean in the context of working with people with dementia; they are central to the arguments presented in this thesis. Furthermore, in my own work and embodied practices there is, I would argue, the phenomenon of a kind of ‘feedback loop’, or inter-subjective dialogue that exists in the relational space between the mover and the witness. This means that mover and witness or in my case, psychotherapist and the person with dementia, are held together in the therapeutic space by the extent to which each influences, is touched by and touches the ‘other’ in a mutually reciprocal way. In other words, and consistent with the idea of ‘building bridges of understanding’, this is yet another example of how ‘bridges’ can be built within the therapeutic space. This is an important phenomenon in the context of the creation of the therapeutic relationship in the therapeutic space, involving inter-subjective and dialectical processes. This idea of ‘feedback loop’ is supported in relation to important work done on touch by a remarkable psychologist and how physical touching of the skin can engender some very powerful responses from the person, in this instance a person without a dementing condition but near to death:

It is a fact familiar to me from frequent observation that the simple reality of being touched with gentle respect can sometimes unleash the most powerful emotional reactions. For even the skin itself possesses a memory, and a simple touch, if it feels *good* and *reaffirming*, can trigger the re-experiencing of the most deep-rooted deprivation and distress (de Hennezel, 1997: 146).

Further, in an inter-disciplinary sense ‘embodiment’ from which ‘embodied’ derives, has been described by a Shiatsu practitioner as ‘a practice of literally touching the present moment with our awareness. The process and experience of being embodied is what draws people to bodywork’ (Pitty, 1996: 8). Thus embodiment is the process whereby something becomes embodied. This is also supported by Smith and Olsen (2006), in their interview with Cohen, a leading and highly skilled movement practitioner in the United States: ‘The process of embodiment is a “being” process not a doing process. It is not a thinking process; it is an awareness process in which the guide and witness dissolve into cellular consciousness’ (Smith and Olsen, 2006: 28). Here Smith, Olsen and Cohen are referring to a sophisticated and very subtle kind of paying attention to the lived body, in relation to Body Mind Centering founded by Cohen herself (Cohen, 1993) and in relation to what Cohen describes as ‘cellular consciousness’. This last reference echoes previous ones, relating to awareness, body-based intelligence and to the importance of ‘being’ rather than ‘doing’ (although both are important) and these concepts are central to both understanding and recognising embodied practices.

Cohen’s reference here to what she describes as ‘cellular consciousness’ (op.cit.: 28) will, I think, be of increasing interest to future researchers. This idea echoes the assertion posed by de Hennezel in her quote above, ‘(f)or even the skin itself possesses a memory’ (op.cit.: 146) and the idea coming from the bio-sciences that individual cells possess innate intelligence and particular attributes: ‘(l)iving cells have a responsive, almost a sentient property. They make their own decisions, undertake complex responses, demonstrating ingeniousness and extraordinary

manipulative skill' (Ford, 2006: 221). In relation to people with dementia with poor brain function, properties attributed to the concept of 'cellular consciousness', may add even greater weight to the significance of embodied practices. They offer direct and experiential ways to better understand the processes whereby the intelligence of the body may contribute to counteracting the ravages of cognitive deficit and ultimately to improving the quality of care practises.

A particular challenge for me is to find ways to transpose these embodied practices and understandings into written form, to make clear to the reader what they look and feel like, when they exist first and foremost in the realm of the lived body and are best experienced and understood in that realm. This in itself is a difficult task further compounded by the existential problem of people with dementia not necessarily being able to speak about their experiences, of occupying their own lived bodies in ways that others can necessarily agree on, accept as representative or valid especially where there is great confusion and ambivalence present. Practically and experientially, this means that from the perspective of the care-staff, it is difficult to test out what people mean in their communications and that: '(y)ou are truly communicating as if your life depended on it' (Killick, 1994: 9). This comes with my own caveat, that the act of communicating is fundamentally an embodied act, resonant with the need to listen and pay attention to non-verbal communications, the lived body and the lived experience of dementia.

Specifically, in relation to people with severe dementia this embodied understanding of perception and reality is of profound importance and recognised by Radden, (2003,

cited in Radden and Fordyce, 2006) in the concept of what she calls a ‘coordination unity’. As she says:

‘....my body is a single entity, pursuing its own, unique spatio-temporal path. In addition though, embodiment provides an everyday, minimal identity or agency which ensures, for example, that when I move, I do so as a coordinated and unified whole. And this unity, we suggest, will be slow to disappear.’ (op.cit.: 79).

I would support this concept of a ‘coordination unity’, especially in relation to people in the later more severe stages of a dementing condition. In Chapters 6 and 7, I shall attempt to show its validity, by reporting that the patients I analysed, in spite of great cognitive loss, were able to move and dance and walk around the room in coordinated ways. They were not stumbling, falling over or otherwise physically out of control. In spite of failing cognitive powers, the unity of the embodied-ness of the person has not deteriorated at the same rate or in the same way. This may be explained in part by the fact that the amygdala or deep and older parts of the human brain play an important autonomic role in this ‘coordination unity’. An on-going process involving movement memory may also contribute here. For example, Brandt and Rich (1995) in their memory studies in this area have argued that neuronal pathways laid down in the course of physical body-based activity over a number of years, are more likely to be retained and remembered, than those laid down through cognitive and more intellectual pursuits. There is a correlation too between the size and magnitude of these neuronal pathways and the loss of their function in relation to the dementia

syndrome attacking them as in Alzheimer's. In other words more strongly myelinated neuronal pathways are likely to remain functional and accessible to the person late into the syndrome; for example a body-memory of how to play golf or cricket.

Renowned neurologist Sacks, (2008) also refers to the importance of the unity of the body and the role of dance especially in relation to people with dementia:

...and if there is no unity, nothing active or interactive going on, our very sense of being embodied may be undermined. But holding someone, making the movements of dance with them, may initiate a dancing response (perhaps in part by the activation of mirror neurons). In this way, patients who are otherwise inaccessible can be animated, enabled to move and to regain, at least for a while, a sense of physical identity and consciousness – a form of consciousness that is perhaps the deepest of all (op.cit.: 382).

I like Sacks' reference here to the links between 'holding someone' in the dance, physical identity and consciousness and the idea that what is being revealed in the process is 'a form of consciousness that is perhaps the deepest of all'. This is a powerful statement, almost a eulogy, and one that echoes my own subjective attempts to describe the significance of the process I have previously described as, 'revealing the hidden humanity through movement, dance and the imagination' (Coaten, 2002: 386). My intention here is not to delve into the psycho-biological or neurological reason for this phenomenon as I am not qualified to do so, rather to argue for what appears very evident in my studies and clinical practice. Older people with dementia still have access to their embodied selves in ways that care-staff and carers need to be

much more aware of and better able to work in response to. I realised that for the person with dementia living paradoxically a richer, more textured, metaphoric, symbolic and aware life, care-staff and carers have more opportunities to work *creatively* in relation to them. Here there is both opportunity and risk: the opportunity to work in more embodied and emotionally congruent ways and the risk that in doing so the care-staff meet special challenges. One of the most significant challenges will be not patronising the person; which together with others, include being better able to move about freely, coherently and *improvisationally* in these embodied realms, able to respond authentically to these emotional and embodied demands (Kontos, 2004).

There follows from this the important and contemporary question regarding how can care-staff be best equipped to meet and engage with the person with dementia in similar embodied, relational and non-verbal ways; in touch with the lived experience of being ‘in’ one’s body so eloquently described by Abram (1996) and Merleau-Ponty (1962). Here lie important reasons why work in this area is so demanding and challenging for those care-staff and carers largely unaware of the importance of these embodied dimensions in the culture of care and perhaps as a result ill-equipped to meet the challenge. It is also true to say, that this is a difficult enough challenge for care-staff fully up to speed with the use of non-verbal and embodied practices. The importance of the embodied and non-verbal perspective as described here, presents a fundamental challenge not only to the dementia care community, but also to the epistemology of bio-medical science that has for so long denied the impact of a phenomenology of perception; one grounded in ‘embodiment’ and ‘embodied practice’ as an empirical reality, and not a metaphoric allusion or ‘mirage’ as

previously referred to by Abram (1996). I am convinced that this ‘mirage’ in thinking in bio-medical science plays a significant role in negatively influencing the culture and values currently found in residential care homes; by for example, inhibiting their ability to meet individual needs as best they can. This is supported by Nyström and Lauritzen, who argued that there was a ‘default model’ (Nyström and Lauritzen, 2005: 314) operating in care institutions, in relation to the provision of activities that focused on incapacity rather than capacity. In other words, the glass was always ‘half empty’, rather than ‘half-full’ and the potential for the individual to communicate effectively and have their needs met would always be hampered by these hegemonic values, as discussed earlier in this chapter. Lintern, Woods and Phair (2000) also observed in their study that interactions between care-staff and residents were primarily focused on the physical care needs of residents, to the detriment of their psychological needs. Residents frequently expressed anxiety or distress, and were ignored by care-staff. Interestingly, interviews carried out in their study pointed to staff equating this anxiety and distress to the person’s medical condition, which they assumed could not be helped or alleviated. This emphasis on the physical aspects of care, to the detriment of the personal, interpersonal and intrapersonal, is a common phenomenon in the literature concerning the care of the person with dementia in general, and also noted by Ward et al., (2005: 17): ‘...our data revealed overwhelmingly, a division between carers and residents, marked by an absence of communication. In terms of actual physical care, residents received adequate provision...However, (taken overall)...then care fell considerably short of expected standards and competencies’. Others to report similar findings include Hill (2004),



Bowie and Mountain, (1993 cited in Ward et. al. 2005), Hallberg et. al. (1990, cited in Ward et.al. 2005), and Kitwood (1997a).

An important function of this thesis is to put up a strong case for articulating and promoting the embodied context of care for the person with dementia which hitherto has been ignored and not considered of importance. This also extends to developing a more effective response to the essential embodied nature of the care relationship with care-staff and how it could be achieved and brought to life in what I call 'Creative Care' (Chapter 8). This approach would model a dialogic, inter-subjective and embodied approach to the provision of care, where communications are more embodied and 'difference' and 'otherness' is better understood and accepted as the 'norm' rather than the exception as has been argued earlier in this thesis. The limitations of the 'bio-medical' or 'default' model would be placed in the context of a fuller, embodied understanding and appreciation of what it means to be human, in the context of the dementing condition. The possibility for 're-menting' needs to be 'held lightly', as an ongoing reality in the context of a much needed shift in awareness and practice, to a more profound understanding of and appreciation for the world-view of the person with dementia. This means that different realities, different viewpoints, different world-views, wants and needs can be appreciated for what they are, the vital expression of people for whom life has become extremely daunting and difficult. Lastly, in this section it is important to mention that embodied practices do not only concern the work of the Dance Movement Psychotherapist or Body-worker. A very important piece of contemporary research with a cohort of four-hundred and sixty-nine subjects all older than seventy-five years, found that participation in leisure

activities including dancing, playing board games and musical instruments (all embodied activities) reduced the risk of dementia in statistically significant ways (Verghese et al., 2003). Results were similar for people with both ATD and VTD.

### **3.5 Further problems in the treatment and understanding of dementia**

This section acknowledges other factors and problems in the recognition, treatment and understanding of dementia, which open up the territory to further question and argument. The bio-medical perspective, for example, cannot be seen as the whole truth, even though I currently work within a National Health Service that predominantly accepts a bio-medical perspective as the whole truth. It is important to be able to view a problem as existential as dementia from a number of different perspectives. For example, there are factors at work within the medical research community that point to attitudes, values and behaviours that at best could be described as self-serving and at worst as wrong. From the early 1900s, when the first researches into the plaques and tangles of Alzheimers Disease were being seen under the microscope, the context of their discovery was being skewed perhaps unconsciously by those directly involved for personal or professional reasons and not purely for the pursuit of knowledge and understanding. Interestingly, this is what happened in the case of Alzheimer and Kraepelin in 1907. It was Kraepelin, Alzheimer's mentor and Director of the Institute where Alzheimer worked who insisted that Alzheimer give his name to the plaques and tangles he originally saw under the microscope (Cheston and Bender 1999, cited in Hill, 2004). Kraepelin sought fame whereas Alzheimer himself considered the plaques and tangles he saw

were simply an aspect of senile dementia, rather than a new pathogen. He bowed to the wishes of his patron and to this day there are still questions as to whether dementia is in fact a disease or, more as Alzheimer thought, simply a part of the ageing process, a condition.

The bio-medical perspective in the care of people with dementia will continue to have, for the foreseeable future, an important role to play while ‘science remains the gold standard of knowledge, and the biomedical model the gold standard of health care’ (Hill, 2004: 228). I make the case here that there needs to come from within the bio-medical science community a better appreciation and understanding of their subtle, negative effects on the quality of care in institutions both here in the United Kingdom and abroad. This is not to diminish what bio-medical science has to offer, rather to enable it, and those who practice it, to be much more aware of its negative or unseen effects. I refer in particular to Vass et al. (2003) and their very important study into communications between the person with dementia and those who care for them. Analysis of 1000 hours of VTR highlighted the person with dementia for whom staff thought unable to communicate:

Careful analysis of long hours of video-recording led to some surprising yet distressing findings: that these individuals did have both verbal and non-verbal means of communication at their disposal. Their signals and messages were totally missed or misunderstood in the course of formal and informal assessments (Vass et. al., 2003: 28).

Vass et al. went on to describe how small ‘jerks’, from one individual in particular, which they had interpreted as meaningful and important, had remained ignored and unseen by care-staff. I think that here is important evidence under research conditions, contributing to the argument that there is within dementia care generally, a paucity of ability to interpret subtlety in verbal and non-verbal communications and this has to change. Kitwood also argued that ‘thousands upon thousands of hours of dementia care work pass by, in which the people involved generally do not understand what they are doing’ (Kitwood and Bredin, 1992: 270). Although this was written in 1992 and care practice has changed a lot since then, nevertheless I still think Kitwood and Bredin’s argument remains valid to this day. There is a great deal still to be done, by way of improving communications especially the emotional and the embodied, plugging a gap that may have been caused in large part by the negative aspects of the reductionist, bio-medical approach and the hegemonic values that currently enshrine the majority of dementia care practised today. I support Hill’s argument that in large part the enshrined and old practices of dementia care are ‘maintained by a number of hegemonies of thought and belief which have come to define a reality of what is and is not possible in the care of people with dementia’ (Hill, 2004: 218). These ‘hegemonies of thought and belief’ are the shadow side of bio-medical science, and they need challenging, in order that the person with dementia can be heard and understood however they choose or are able to communicate.

What might be stopping or getting in the way of a more embodied approach to health care and the care of older people in particular? From a sociologist’s point of view it is

interesting that while the body is necessarily at the heart of health care, its very position has meant that at times it has been ‘paradoxically, overlooked - so completely does it occupy the field of vision’ (Twigg, 2006: 1). Twigg here acknowledges the centrality of the body in the ‘field of vision’ and yet points up the fact that it has at the same time been ignored. I think Twigg is referring here to the lack of a fundamentally embodied approach in the care of older people and older bodies, which views them in distant and alienated ways, ‘the body becomes alien from the self, an object of observation and intervention by others’ (p.2). In so doing these ways are accepting of, ‘(a) range of, largely negative, meanings (being) read onto the aged or disabled body, which is then treated as the source of these meanings’ (p.29). In Twigg’s argument we have what could be described as a kind of self-perpetuating cycle of disembodied, ageist, sexist, cultural and gender-based attitudes that have kept the body in health and social care in a marginalised place. I think this makes an effective parallel with Kitwood’s (1997a: 45) idea of a ‘malignant social psychology’, referred to earlier, that similarly diminishes personhood in self-perpetuating, disembodied and cyclic ways. What is of immense importance however, in the health care field as demonstrated by these arguments, is for those who provide and deliver the care for older people with dementia to do so with substantially increased funding, training, pay and embodied awareness and understanding. With increased knowledge and awareness about how easy it is to undermine the frail and very vulnerable people in these cyclic and de-personalising ways, care staff should be better supported to develop and maintain more person-centred care practices.

Another important problem evidenced by Harding and Palfrey (1997) is that dementia syndrome, far from being a disease entity in its own right, is predominantly a socially and medically constructed phenomenon. They argue that there is, for example, no absolute causal relationship between brain pathology and dementia, which is a necessary part of disease classification within the standard disease model. They claim that diagnosis is made predominantly on the basis of behaviour rather than physical symptoms, and that the bio-medical perspective is indeed one of several possible explanations; also that it is historically, socially and culturally based and as such open to criticism. These, coupled with the others presented in this section, are interesting arguments and worth exploring further, because in becoming more aware of alternatives to the biomedical view, a more realistic picture can be built up of what is in fact a very complex situation. By thinking more widely, and not accepting the bio-medical view as the only approach to the study and practice of dementia care, other horizons open up and there can emerge, as discussed fully in Chapter 2, a much greater appreciation for the importance of 'difference' and 'otherness' in the provision of services.

There are also the economic considerations of finding a dementia 'cure-all' type drug. Again, Harding and Palfrey (1997) recognise the need for a diagnostic tool which 'can accurately identify the existence of the disease, its severity and its prognosis' (p.37). Whilst this is highly important as an aim within the bio-medical fraternity of experts and researchers, the dementia research laboratories of the world compete to find the wonder drug that will be a cure-all. What is currently being done in that arena is therefore motivated by a possible financial windfall to the company able to

produce the drug. Current hopes are pinned on a number of different approaches with one of the most promising a passive vaccine ('bapineuzumab') that will supply 'anti-amyloid antibodies directly to the immune system rather than stimulating the immune system to produce its own' (Bradley, 2009: 20/21). In other words, laboratories motivated by profit rather than contribution to knowledge for the good of humanity vie with each other to produce the cure-all for someone with a dementing condition. This, in all likelihood, will result in a significant delay for the person with dementia receiving benefits from any new medication. Laboratories, and the companies that own them, may decide for instance, to withhold the 'secrets' (sic), the patents necessary to share the knowledge they possess amongst their peers and colleagues. They could do this for commercial or profit-related motives, rather than for the need to improve the lives of all people with dementia by working together in an altruistic way, sharing information and knowledge as needed. The vaccine creating and making process thus creates levels of secrecy, motivated by profit and greed, resulting in increased levels of hype and expectation amongst the potential 'market' (sic) of dementia sufferers. Increased levels of hype and expectation are also important factors likely to raise the final cost to the consumer of any product aiming to reduce suffering or improve treatment in this area.

In a remarkable work, Shenk (2002) writes about the importance of naming a disease. Once it is named, he says, it acquires a certain status, and enables the medical profession to rally round to defeat or otherwise attempt to cure it. Having a diagnosis means the disease acquires a name and this from a social constructionist viewpoint is

of equal importance to the patient, as it is to the medical professional. It becomes known about and acquires a unique identity as well. Shenk also says:

Because of the elusive nature of the disease, the name is often the only available emblem. Once accepted, specific names quickly come to dominate social reality. The flavour of the name can make a real difference in how the disease is perceived and acted on (Shenk, 2002: 80).

The name 'Dementia', or 'Alzheimers', may have an effect in the general population, now, conjuring up what the term 'The Plague' may have had to people in the middle-ages. The Plague conjured fear in the population; sufferers were isolated, and stigmatised towns like Eyam in Derbyshire had a 'plague stone', where food was left for villagers so the 'clean' and the 'unclean' would not come into contact with each other. 'Alzheimer's' has become synonymous with an incurable disease. If you get it, you are progressively going to lose your mind: you are going to become 'mad' in the popular imagination. The danger in naming is that the map gets confused with the territory and the person with dementia becomes tarnished and stigmatised with this label in the same way. There are no subtle individual variations, no hope, no possibility of seeing dementia syndrome as a condition one can indeed learn to live with; coming to terms with the changes that will be needed for example in activities of daily living, rather like someone with a disability learns to come to terms with their 'embodied' reality. Names and naming can therefore have an important effect on how the condition is perceived and responded to in the general population.



### **3.6 Concluding thoughts**

I have looked at three main approaches to dementia plus several other important problems. It is necessary I think to be able to acknowledge these differing perspectives, attitudes, values and belief systems in helping me, and hopefully others better shift between differing viewpoints. Being able to shift perspective highlights the importance of ‘Building Bridges of Understanding’, between the known and the not-yet-known, the loved and the un-loved, with the added recognition here, that names and naming play a role in stigmatising dementia. A greater acceptance of and appreciation for ‘otherness’ and ‘difference’, in the context of the care of the person with dementia is urgently needed especially in relation to bio-medical approaches as discussed in this thesis.

I also want to draw attention to how Dance Movement Psychotherapy might find its ‘embodied’ place, alongside the bio-medical and psychosocial epistemologies. In exciting work, with important implications for the training of Dance Movement Psychotherapists, Best (2003) describes being able to take different relational positions in viewing a clinical or practice problem. She describes the importance of attempting to shift perspective from one mode to another, especially when there is a sense of difficulty or stuckness present: ‘I anticipate deepening, or broadening, the methods of data collection during shifts between modalities e.g. movement, drawing, talking, listening, playing with objects, sculpting’ (Best, 2003: 20). This ‘broadening and deepening’ approach she describes as ‘Interactional Shaping’ (p.19), which brings to awareness the ‘embodied’ nature of the therapist with their prejudices,

different viewpoints and attitudes. From a bio-medical perspective this would probably remain incomprehensible, as it would be impossible to differentiate what was having the effect. Was it the activity itself? Or was it the personality of the therapist? (Perrin, 1998). A mind/body dualism would want to separate out and label the constituent parts rather than accept the relational aspects between the constituent parts of being the greatest value. In my view, Best's argument helps develop appreciation for and understanding of, the complexities of what she describes as the 'three dimensional nature of relationship in observed action' (Best, 2003: 19) and its particular relevance in dementia care. I constantly see as psychotherapist in my clinical practice evidence of the three-dimensional nature of relationship through 'observed action', and in the process consider myself challenged to respond well to it. I try using different modalities and perspectives. I switch between movement and dance techniques and music, and reminiscence and song and narrative including storytelling and visual-art. I have yet to use drawing, however I know artists who use drawing and other visual art techniques to great effect in getting to meet the person as they would like to be met. There is an important 'embodied' element in Best's work that provides evidence for how psychotherapists and care-staff can use different sensory modalities to enable communication and self-expression. I think Best's work is of particular significance in relation to my own and a helpful way of leading into the next chapter. This will discuss the role and importance of Dance Movement Psychotherapy in contributing to raising the quality of dementia care; where life for the person with dementia can become more embodied, more relational and better informed by the implementation of these embodied perspectives.

## **Chapter 4**

### **Dance Movement Psychotherapy**

#### **4.1 Introduction**

This chapter aims to describe, analyse and discuss the history, theory and practice of Dance Movement Psychotherapy (DMP) and its relevance to people with dementia and their professional care staff. It aims also to place DMP within a contemporary context, as embodied practice, drawing on its history and the work of pioneers in the field. These are pioneers both national and international who have sought to establish some of the key processes at work in this specialist area. This chapter discusses the development of various concepts, all of which I have found helpful in describing and analysing DMP and in looking forward to making it available to a wider audience. In Chapter 6 (Section 6.7) I discuss in considerable detail what a DMP session looks like in practise, and I refer the reader forward to this chapter for practical details of session content and evaluation.

DMP is a relatively new profession and is also, ‘an interdisciplinary field: a hybrid of the art of dance and the science of psychology adapted to human service’ (Goodill, 2005: 21). In the United Kingdom, numbers of Dance Movement Psychotherapists are growing, with different Universities and Colleges (Roehampton, Derby and Edinburgh) providing a range of courses. It has its roots both here in the UK and in the United States (US) in the 1940s. Since then, a growing evidence base has contributed much to what is known about the importance of non-verbal, embodied practices with

a variety of groups and individuals in hospitals and the community. Significant developments have been made, nationally and internationally. This thesis attempts to build on the DMP foundations already laid by my predecessors; while contributing to a growing knowledge and skills base, in better understanding DMP in relation to people with dementia and their professional care staff.

## **4.2 Dance Movement Psychotherapy – History, Theory and Practice**

The roots of dance as therapy arguably go back to the earliest of times in human history, when dance was used by indigenous peoples around the world to celebrate rituals and events of all kinds. These included, for example, rituals of fertility, birth and marriage, or to celebrate a successful hunt. Rituals involving dance were also used to heal and treat illness and disease, usually carried out by specially trained and gifted shamans using shamanic practices (Frazier, 1976). One such practice, described by Frazier, was for the shaman or ‘devil-dancer’ to be called in when the physicians in ‘Cingalese’ society had not succeeded, ‘...who by making offerings to the devils, and dancing in the masks appropriate to them, conjure(s) these demons of disease, one after the other, out of the sick man’s body and into his own’ (Frazier, 1976: 711). Following this appropriation of the offending ‘demons’, the shaman retires to a place separate from the community, and proceeds by way of ritual and shamanic practice to rid himself of whatever he believes himself to be possessed by. In our current, modern western technological approaches to disease and ill-health, these shamanic practices may represent belief systems that have no place in today’s world. They are ostensibly irrational, unscientific and therefore their efficacy for

those directly involved remains hard to investigate, let alone prove. Hanna, however, a distinguished dance therapist and anthropologist warns against being dismissive towards that which we don't at first understand:

Effective therapy requires an understanding of the cultural and ecological patterns governing a client's life, the different concepts of mind, body, parts, time, space, effort, color, texture, and other properties found in everyday life and the arts, as well as what movement is done where, when, how, and with and to whom (Hanna, 1990: 118).

The skill of the psychotherapist in the therapeutic relationship means that they are able and willing to perceive and accept 'otherness' and 'difference' in the client, without 'difference' being interpreted as wrong or unacceptable (Hanna, 1990). This implies an acceptance of a 'multiplicity' of ways to practise, and is key to a working and effective therapeutic process and relationship in modern DMP, that links directly to the work of the early pioneers (see Chace below). The client or patient within the DMP process needs to know that their personhood will be accepted, and wherever possible understood by the therapist; some of which will be 'known' and some still, 'yet to be known'. This expression of client need within the therapeutic relationship links back to Chapter 2, where I discussed the role of anthropology and ethnography in helping us learn as psychotherapists, to be more accepting of different cultural, and individual patterns of communication and behaviour.

Taking this understanding a step further, it is interesting to note that there are parallels between ancient shamanic practices and modern day DMP. The 'Cingalese'

‘devil-dancer’ in Frazier’s (1976) account first of all attempts to differentiate the different ‘demons’ possessing the person. He ‘conjures these demons of disease’ and uses masks in the process to symbolise them. This is similar to the modern day attempt by the Dance Movement Psychotherapist to analyse and differentiate the different aspects of whatever symptoms or problems are manifesting for the person. The contemporary DMP would probably not use masks in this ritual way, but would rather attempt to differentiate symptoms of distress within a more conceptual and systematised framework or approach. Decisions would be made regarding future treatment in relation to meeting individual needs and the therapist’s training and experience. The therapist would also not allow themselves to be possessed by the ‘demons’ like the ‘devil-dancer’ in Frazier’s description. Having defined and differentiated the different aspects of the problem or problems, the psychotherapist would then enter into some kind of an agreed contract with the person, relating to proposed treatment, duration, likely outcomes and fee. The ‘devil-dancer’, according to Frazier (1976), returns to the man after he has completed his task of ridding himself of the ‘demons’ to collect his fee. For the man ‘treated’ by the ‘devil-dancer’ and the person treated by DMP, both entail a suspension of disbelief; meaning that both will ‘project’, in the psychological sense, onto shaman or therapist, that their skills and their ‘name’ in the field, will result in the desired outcome. They are prepared for a time to suspend their disbelief that the therapist or ‘devil-dancer’ will not be effective in their work. In both ancient and modern healing practices using music, movement and dance as therapy, there is the upholding of a ‘belief-system’, that the method and approach, however carried out, will work as evidenced by people getting better and in the case of the man ‘treated’ by the ‘devil-dancer’ being cured (

Frazier, 1976).

Dance Therapy in the US or Dance Movement Psychotherapy in the UK are names given to a body of knowledge, skills and experience, developed over years, that use movement and dance to help treat people who may be suffering physical or mental ill-health. Contemporary DMP practice and training is now effectively and clearly defined and it is spreading around the world with training programmes in Israel, Belgium, Australia, Germany and Italy to name a few. The current definition of DMP is as follows: ‘an arts therapy that enables clients to express themselves creatively, foster relationships, work through their difficulties and develop their strengths’ (ADMP (UK), 2002). This is not dissimilar to a definition of psychotherapy in relation to people with dementia:

‘It is a process that occurs in an interpersonal context, as a result of which a person is enabled to change his or her way of being in the world, or relating to others, of choosing and executing projects. In psychotherapy old wounds are healed, hidden conflicts resolved, and unfulfilled potential brought out. Hence life becomes more satisfying, secure and productive’ (Kitwood, 1990: 43).

I think a central aspect of both definitions is the focus of attention on developing strengths and bringing out unfulfilled potential. In dementia this aspect takes on particular urgency, as there is likely to be evidence of potentials still available to the person which may need the ‘other’ to help act in a mediatory or ‘bridging role’, which has been a strong through-line of argument throughout this thesis.

DMP evolved in the modern era out of the early work of Marian Chace and other pioneers in the US and the UK. Working in a psychiatric hospital in Washington D.C. for many years, beginning in the 1940s, Chace made some important discoveries about how split-off from their ‘embodied’ natures people in psychiatric institutions had become. She developed and tested her ideas and theories, essentially through a process of trial and error, working with patients with a wide variety of problems, including violence and hysteria (Chaiklin and Schmais, 1986). By using music, movement and dance, Chace was able to re-connect patients with their own sense of themselves as people with an ‘embodied’ and ‘embodying’ nature. In the process she returned to them a sense of relationship and connection with their bodies and with the resources and unused potential that she believed each person possessed in order for them to get well again (Chaiklin and Schmais, 1986). She brought empowerment in place of powerlessness, hope and a sense of purpose and meaning, in place of hopelessness and helplessness. ‘Rather than relying on theoretical models that stress pathology, she sought out motion and health. Her profound understanding of rhythmic movement led her to create a method for contacting and sparking the life force of those afraid and alienated’ (Chaiklin and Schmais, 1986: 26). From a more contemporary perspective this argument in support of the importance of embodied practices is still very relevant, and echoed here in modern medical practice by Kleinman: ‘...modern medical practice drives the doctor’s attention away from the lived experience of the patient, and with it from key dimensions in how illness should be understood’ (Kleinman 1988, cited in Twigg 2006: 83). Chace’s developments were significant developments for the time, and the medical staff in the institutions where she worked gradually noticed beneficial changes in the patients, which they



had not been able to achieve themselves. Over time, she did more and more work of this type, giving lectures on the subject and eventually founding the American Dance Therapy Association (ADTA). She became its first President between 1966 and 1968.

Somewhat typically of early pioneers, Chace (1975) wrote very little about her work, and what little she did write contained no references or bibliography, 'though it is evident that much thought and scholarship went into the development of her work' (Chaiklin and Schmais, 1986: 16). Chace is well known for her claim that, 'the most basic concept and the one from which all others flow, is that dance is communication and thus, fulfils a basic human need' (Chaiklin and Schmais, 1986: 16). In the context of contemporary DMP this discovery by Chace may seem obvious; but it would be a mistake to under-estimate the originality of Chace's ideas. At the time Chace began her pioneering work and for a considerable period of time afterwards, the concept of 'dance is communication' would have been contrary to received wisdom. Dance in the 1940s in the US and elsewhere was primarily associated with expressions of technique and the image of 'body beautiful', making choreographed shapes in choreographed performance pieces. Indeed, Chace's own background was with the Denishawn Dance Company, and dance as performance would have been very familiar to her. Chace's singular contribution to the founding of what later became Dance Movement Therapy and Dance Movement Psychotherapy here in the UK in 2008, was the understanding based on her practice and experience, that dance was about communication and the expression of basic human needs, both distinct and separate from 'dance as performance'. Dance could be used as a form of therapy and a medium through which to communicate, reach and even treat people with mental-

health problems. These were people for whom verbal communications had little or no relevance, or who had lost confidence that anyone would ever be able to reach and meet them as they needed to be met. This was within the conventions of bio-medical science, as expressed through traditional psychiatric treatment. For the time, Chace's ideas were very significant non-verbal developments in mental-health treatments, which gained her recognition for her achievements. As there were no Dance Movement Therapy training courses at that time, Chace gained a following of students and apprentices through to the end of her life, such was the strength of her experience, her skill and reputation in the field. These students and apprentices included Chaiklin who, along with Schmais, later went on to systematically identify and document what they understood her methodology to be about (Chaiklin and Schmais, 1986).

I have chosen to discuss the work of Chace in particular, as her work and approach have influenced the development of my own practice to a significant degree and to the session content and structure studied here (see Chapter 6 Section 6.7). While I was not able to train with Chace directly, I was able to learn directly and experientially from those, like Gabrielle Parker in the UK and Joanna Harris and Marcia Leventhal in the US, who had learned from Chace herself and her students. This reflects an on-going and incremental approach to practice development within DMP that pioneers both in the US and in the UK have passed on their skills, techniques and ideas to others, who in turn have taken and adapted them to their own working practices. These become subtly changed and adapted in the process and passed on in a like manner. What makes Chace of such importance, is that she was

the first of the Dance Movement Therapy pioneers in the US to explore some of the key concepts of movement and dance as a healing art, that was later to become formalised as the use of dance and movement as a distinct arts therapy.

#### **4.2.1 The Chace Approach to Dance Movement Psychotherapy**

Chace developed what have been identified as four key concepts, namely ‘Body Action’, ‘Symbolism’, ‘Therapeutic Movement Relationship’ and ‘Rhythmic Group Activity’ (Chaiklin and Schmais, 1986). These have been delineated by Chaiklin and Schmais, who are careful to stress that these different concepts all work together in one unified whole and that each key concept can be further broken down into specific goals which I have chosen not to discuss here for reasons of brevity (Chaiklin and Schmais, 1986). Chace believed that understanding and working with ‘Body Action’, in and through movement, was essential to bringing connection and relationship to previously ‘disconnected’ parts of the body. Parts of the body that were held in a high state of tension could be influenced by motility, by changing breathing patterns, enabling emotional release and expression (Chaiklin and Schmais, 1986: 17). Although originally conceived back in the 1940s and 50s, Chace’s work is still relevant today and her legacy is echoed in the following words by contemporary US pioneers of DMP in dementia care: ‘The dance/movement therapy programme at University Hospitals Health System and Heather Hill Hospital and Health Partnership involves the intentional and compassionate use of breath, movement, touch and dance to promote the physical, psychological, emotional and spiritual well-being of each person’ (Shustik and Thompson, 2001: 49).

‘Symbolism’, the second key concept, was for Chace, ‘a medium by which a patient can recall, re-enact and re-experience. Some problems can be worked through on a purely symbolic level’ (Chaiklin and Schmais, 1986: 18). This means that through the movement and dance experience, people’s inner feelings and unconscious desires, wants and needs can be expressed symbolically by a movement phrase, gesture, sequence or action. This in turn gives the therapist the unique ability to work in embodied and non-verbal ways to enable communication of that for which there may be no other legitimate form of expression for the person. I discuss this in more detail later in this chapter ( see Section 4.6). Also in Chapter 7 (Section 7.4.1) I describe the findings of my own analysis of the Video Tape Recording (VTR), in relation to the identification of particular themes (Appendix B). Theme 6 for instance, refers to ‘Maintaining Identity and Symbol Formation’ and the links I discovered in the research, between expressions of identity for the person with dementia and particular movements, gestures and expressions that had a symbolic basis to them. In my own practice and analysis of the VTR, I was able to connect my researches and experience directly back to the early pioneering work of Chace and by so doing acknowledge the relevance of her work to DMP practice today.

The third key concept defined as ‘The Therapeutic Movement Relationship’ (Chaiklin and Schmais, 1986: 18) is crucial, because without it the other key concepts probably would not work as well, if at all. Chace was able to sense, intuit and carefully feel her way into a movement-based relationship and dialogue with ‘the other’, however confused, angry, upset or distant and depressed they appeared to be.

This was essentially about the establishing of a non-verbal movement relationship, providing acceptance of the person at a deep level that is acknowledged by both patient and therapist. An example of how this relationship could be built in practice was through the careful application of a technique now called ‘Mirroring’ (Levy, 1992, cited in Shustik and Thompson, 2001: 53), which Chace also pioneered and which means being in touch directly in embodied and emotional ways with what another is experiencing. Mirroring is an experience of emotional and embodied attunement that is quite different from mimicry with which it could easily be confused. As a form of non-verbal body synchrony, it attempts to make genuine contact with the ‘other’, without any form of coercion or pressure onto the other person. I use this technique on a regular basis in my clinical practice and have also used it extensively in this study and during the sessions I ran and the one analysed and discussed in Chapter 7.

‘Rhythmic Group Activity’ is the last of the four key concepts and also vital to my own contemporary DMP practice. A group moving rhythmically together provides a shared form of activity that draws people in, ‘as each member draws from the common pool of energy and experiences a heightened sense of strength and security’ (Chaiklin and Schmais, 1986: 19). I also think that for people with dementia it offers an embodied kind of organising principle, which links well with what Radden has described as a ‘Co-ordination Unity’ (Radden 2003, cited in Radden and Fordyce, 2006) (see Chapter 3 Section 3.4). ‘Rhythmic Group Activity’ certainly brings people together as clearly seen in the data analysis and also described in Chapter 7 (Appendix B) under Theme 4b. Theme 4b, ‘Importance of Rhythmic Movement’,

was the fourth most occurring theme with 22 occurrences in the session and therefore of considerable importance in the session results and analysis.

Chace was also instrumental in the development of the idea of a particular sequence or session structure, described as ‘warm-up’, ‘central development’ and ‘closure’ (Chaiklin and Schmais, 1986). This session structure was also used in the session evaluated and described in this study. ‘Warm- up’ refers to a process of making initial contact with and between people, establishing open-ness and trust in the group and setting up group-based rhythmic group activity often using music or even body-based percussion exercises. ‘Central Development’ gradually draws attention to, and develops emotional themes, that have begun to surface in the group using imagery, verbal questioning and movement. This middle section allows, wherever possible, individuals to take responsibility for their own movement and dance experiences, going deeper into particular movement qualities, feelings, images, associations and memories. Sometimes it is carried out in the large group or in pairs, threes or even solo. It is evident that in practice this is very skilful work:

The therapist moves from one patient to another reflecting varied rhythms and moods. She is sensitive to the length of time needed for each person, anticipates the degree of tolerance for closeness, for communication, for touch, and provides closure before the patient feels threatened or needs to make a move to withdraw (Chaiklin and Schmais, 1986: 23).

‘Closure’ refers to the gradual process of finishing a session, which, according to Levy (1988), was a time for verbally sharing what had come up for individuals and

wherever possible reflecting on its meaning and importance before the group separated and the session closed. 'Closure' in relation to this study draws on the Chace approach, however with people with dementia who are cognitively compromised by the condition it is difficult to expect verbal sharing, at a level possible with other groups, for example, people with functional mental-health problems such as anxiety and depression who are more cognitively able. By way of replacement for verbal sharing, non-verbal activities such as holding hands passing a gentle squeeze around the group, and thanking participants for coming is achievable. A display of the props used in the session, placed carefully on the floor in the centre of the circle can provide a visually stimulating experience for participants. They can be asked to look at the display and find any words or associations or memories that come to mind, by way of re-membering what has taken place. In addition the singing of songs, while either sat in chairs or standing, offers a valuable way of moving towards the close of the session. Singing enables a gentle winding-down of the movement and dance elements of the session while remaining of specific physiological value to the person by way of supporting breathing and psychological process in terms of maintaining well-being, identity and word recall. As McMorland (1998) argues in describing the value of hymn-singing for 'Elizabeth', 'Her need for security and love is given through another person's voice gently reminding her of what her being knows. Elizabeth is able to sing the words even though she has now lost everyday words of communication' (McMorland, 1998: 117). Interestingly hymn-singing was also an important aspect of this study as later described in Chapter 7 (Section 7.4.6) in relation to Arthur.

#### **4.2.2 Laban and Laban Movement Analysis**

I shall here describe the work of Rudolf von Laban as a key player in modern dance and in better understanding the dynamics of human movement, here in the UK. His work had begun in Germany before the Second World War when he was commissioned by the German Government to carry out time and motion studies on factory workers (Laban, 1967). The quest of the German Government was to better understand human movement in the workplace in order to increase worker productivity. Laban however, fled Germany in 1937 and on his arrival in the UK stayed courtesy of the Elmhirst Family at Dartington Hall, where he worked with the Joos-Leeder Ballet Company that was also resident at Dartington.

What makes Laban of such interest is that he contributed not only to the development of what later became known as Laban Movement Analysis, now a valuable analytical tool in contemporary DMP, but also to the evolution of modern dance. One of his earliest pupils was Mary Wigman who subsequently started and ran her own dance company in Germany. Wigman was noted at the time for her free and expressive movement style that incorporated strong emotional influences. Her work was to influence many others both in Europe and the US while the significance of Laban's work in modern dance also laid the foundations of what became known as 'Community Dance' here in the UK.

Movement observation and analysis was initially pioneered by Laban (1950) and developed by others (North, 1972, Lamb and Watson, 1979) to identify movement



preferences, strengths and weaknesses in the individual. It is important that this process of attending to movement observation and analysis is understood as both a highly complex and embodied experience. Witnessing different movement qualities, expressed in different spatial directions with many different combinations of what Laban called 'efforts' (Laban, 1950), is a highly skilled act and requires an in-depth understanding of, and training in, what in contemporary DMP is now called Laban Movement Analysis (LMA), incorporating the in-depth work and studies of other contemporaries of Laban (North, 1972, Lamb and Watson, 1979, Kestenberg and Sossin, 1979, Bartenieff and Lewis, 1980). The purpose of LMA is to provide a detailed and systematic framework for observing and analysing qualitative change in body movement, against which the strengths and weaknesses of any individual mover can be set. These are then identified and framed within what is described as a movement profile. The profile represents a whole series of scales that break movement and its essential qualities down into its constituent parts. For example Laban described four major 'Efforts' identified as Space (either bound or free), Time (either sudden or sustained), Weight (either strong or light), and Flow (either bound or free) that provided a framework within which movement qualities could be described. He also identified the different movement planes, or 'Space Harmony', through which people move; the first plane is the sagittal (or wheel) plane, the second is the vertical plane, the third the horizontal (Laban, 1980). Also of particular interest are the ways through which movement identified by these different scales and planes enables psychophysical aspects and underlying meanings to be revealed. These psychophysical relationships between movement and the presentation of unconscious material as understood by the Dance Movement Psychotherapist provide an essential

resource and tool-kit when DMP is used as a medium for treatment. ‘Movement, due to its developmentally based origins and potential capacity for eliciting unconscious material, is a highly powerful medium for the therapist to assess and employ within the therapeutic process’ (Bernstein, 1986: 175). Bernstein goes on to describe the process and importance of what she calls ‘subtle movement reflection’ (p.175), to enable the person undergoing DMP to be able to have reflected back to them by the psychotherapist movement material or motifs that may for example link back to the pre-verbal development stage of the infant. This early time in our development as human beings is difficult to access since psychological, physical, behavioural and emotional difficulties or trauma may have their origins in our first attachment bonds, ably described in the work of Winnicott (1971) and Bowlby (1988). This means that the therapist via the movement medium can help access long buried movement memories and preferences that have psycho-physical roots and that may, by being brought into awareness, be of great therapeutic importance to the person undergoing Dance Movement Psychotherapy.

The use of LMA is vital to what DMP is able to achieve, almost entirely in relation to the embodied and non-verbal realms of human movement and communication. LMA is not unique to DMP however, as Lamb and colleagues have pioneered its use involving management and leadership development, under the auspices of ‘Action Profiling’. They have also used it to build what Lamb (Lamb, 1985: 93) calls ‘balanced innovation teams’, within the context of team-building in the commercial sector.

### **4.3 The importance of the Dance Movement Psychotherapy pioneers and their legacy**

Contemporary DMP continues to be influenced by the work of the early pioneers in the US and the UK. However, it has now become more clearly defined and governed; there is a Code of Practice, an application to Parliament for State Registration and other forms of governance here in the UK. In a ‘Special Edition Introduction’, the current Chairperson of the Association of Dance Movement Psychotherapy (ADMP as of June 2008) referred to the inclusion of biographies by some of these early pioneers in the latest edition of the newsletter by saying, ‘Raising awareness of our DMP history through these personal stories enhances a sense of belonging to a creative and healing community’ (Unkovich, 2008: 8). This awareness includes the pioneers who gave the movement what it has today, as well as to current practitioners working in the field and students currently in training.

Bloom, a senior dance therapist, has said, ‘We are *all* pioneers, and I believe the terrain is extremely fertile’ (Unkovich, 2008: 8). This challenges the idea that pioneers are always of the past and argues that in order for the profession to grow and develop, all of us are working to further the growth of knowledge and development. This statement by Bloom encourages and supports the development of a pro-active learning culture within DMP, with a growing number of recently trained Dance Movement Psychotherapists currently practising and those currently in training learning how to do so.

Also of note in assessing the importance of the DMP pioneers both from the past and of today, is how they contribute to enabling this relatively new profession to become better known especially in relation to its importance in the dementia care field. For example, Kitwood (1997a) has argued most eloquently that dementia care practice needs to be transformed and that, '(a)bove all else a reconsideration of dementia invites us to a fresh understanding of what it is to be a person' (Kitwood, 1997a: 144). The work of the psychotherapist by way of the creative arts therapies invites the client in to a fresh understanding of who they are in the world. By working together with those in contemporary dementia care practice who are committed to this 'fresh understanding' (Op cit: 144) the Dance Movement Psychotherapist as embodied psychotherapist can make perhaps their most valuable and long lasting contribution. They can, through the application of embodied practices and by way of the experience of the lived body as psychotherapeutically framed, contribute to what Kitwood has boldly called for in: 'the positive transformation of care practice – if it occurs on a widespread scale – will undermine all facile forms of determinism, and interrupt the obsessional search for technical fixes to human problems' (Op cit: 144). This is a bold challenge to changing care practices for the better and there is evidence that Dancers, Dance Movement Psychotherapists and others are indeed responding to Kitwood's challenge as a pioneer in dementia care (Coaten 2001, 2002a, 2002b, Crichton 1997, Hill 2001, Perrin 1998, Shustik and Thompson 2001).

In DMP as embodied psychotherapy there is also a sense that in spite of the confusion, it is still possible to be surprised by what takes place and also in what people with dementia still remain capable of, however frail:

In the dance it was possible still to see and make contact with the individual. Despite the doom and gloom attached to dementia and the real hardships of the disease, people retained an ability to surprise and to do things that we did not think them capable of (Hill, 2001: 1).

A counter argument could be found that while ‘being surprised’ and doing things one is not thought capable of is noted, surely with such a frail and vulnerable population, this activity is hardly momentous or valuable in the long term? These people with dementia are going to die, perhaps sooner rather than later, so why bother with these arts based approaches? As researcher/practitioner I question the validity of this counter-argument on the grounds that a) the problem of how to reach the person, effectively and well is not going to go away, given the projected numbers of people living with dementia in the UK expected to grow very significantly indeed (Alzheimer’s Society, 2006/7); the problem therefore is going to increase in severity and b) an approach that undermines the personhood of a person with dementia by way of diminishing their contribution however small is ethically, conscientiously and professionally untenable and in contravention of our Code of Professional Practice (ADMP (UK), 2003). Gibson (1999) too is unequivocal in her powerful argument about what happens if we do nothing and we do not respond to the person however best we can:

The consequences of doing nothing, however, are not neutral. Inaction conveys not nothing, but rather the destructive message that the person with dementia is not worth bothering with and is in fact a non-person, an object, an it. Our non-

action conveys the message “you are not human”. So the person with dementia experiences further anxiety, further withdrawal and further deterioration because of our failure to reach out, to share, to establish common ground (Gibson, 1999: 21).

I would agree therefore that doing nothing is untenable from a psychotherapeutic, moral and person-centred point of view. Finally, the legacy of the pioneers of DMP has been to enable Dance Movement Psychotherapists to be better and more fully equipped to face the challenges posed by severely confused and vulnerable people and how best to meet their psychological and emotional needs by way of the lived body.

#### **4.4 Dance Movement Psychotherapy as embodied psychotherapy**

The professional association for DMP in the UK, the Association for Dance Movement Psychotherapy (ADMP), has in 2008 been given this new name by its membership, in part reflecting the need for DMP to be a part of the world of psychotherapy rather than ‘therapy’ per se. This replaces the previous title of Association for Dance Movement Therapy. I think this is essential and part of the process of DMP in the UK, clarifying, aligning and asserting its relationship to the development of what I am choosing to call an ‘embodied psychotherapy’.

What do I mean by DMP as ‘embodied psychotherapy’ and why is it important to frame DMP this way? First of all, DMP is distinct from the talking psychotherapies as it does not rely primarily on verbal expression. It relies on the creation of the ‘therapeutic relationship’ (Chaiklin and Schmais, 1986) which the ADMP currently

calls ‘developing a trusting relationship’ (ADMP (UK), 2002) or ‘tuning-in’, within a context of body movement and embodied practice. It requires the Dance Movement Psychotherapist to attend to the person’s movements and their physical presence and to tune in to the person. I consider it important to refer to DMP as ‘embodied psychotherapy’ in order to support my argument for its application as a treatment and rehabilitative medium for people with early through to late-stage dementia syndrome. This means that within the dementia care community its relevance needs to be evidenced and communicated with clear examples of its benefits for people living with dementia and their care-staff. Viewed as ‘embodied psychotherapy’, there is a greater chance that it will be accepted within the dementia care community as having a special relevance. In the literature Melsom (1999), for example, cited four aspects of DMP making it different from other psycho-social interventions in the bio-medical setting. These are:

- the incorporation of the body into the psychotherapeutic process.
- the building of a relationship with the patient’s body.
- the promotion of the establishment or re-establishment of a positive relationship between the patient and his or her body, and
- the use of creative movement expression to promote the expression of health (Melsom, 1999, cited in Goodill 2005: 31).

These four aspects of DMP are also valuable because they draw attention to the embodied and special nature of the psychotherapeutic process as practised by the Dance Movement Psychotherapist. The next section will draw attention to and

describe the importance of metaphor and the movement metaphor in particular, that is unique to DMP as embodied psychotherapy.

#### **4.5 DMP and Metaphor**

Metaphor refers to aspects of the psyche that arise during the process of DMP, inform its progress and outcome and contribute to the resolution of problems. According to Bartal and Ne'eman (1993: 20) a metaphor is,

a descriptive term or phrase applied to an object or action to which it is not literally applicable: describing one thing in terms of another. Working through metaphor creates a rich kaleidoscope of experience; it is a mirror of the body, mind and soul that reveals unseen parts of ourselves.

This useful definition by practising Dance Movement Psychotherapists acknowledges the literary and descriptive, together with the embodied aspects of the nature of metaphor. The embodied aspects are especially relevant in the context of DMP practise. Also another contemporary UK pioneer of DMP argues that the movement metaphor is at the heart of DMP: 'DMP is a psychotherapy in its own right, mediated by the creative process within a therapeutic relationship, and using movement metaphor as its central tool' (Meekums, 2002: 36). The movement metaphor in this context as a 'central tool' refers to a movement sequence, a posture, a gesture, that may have an underlying meaning expressed in and/or through the body. The movement metaphor has been triggered or brought into the present moment by the actions of the therapist and patient acting in the inter-subjective space that is the



therapeutic relationship. The metaphor has been able to jump across between the visible and the invisible, the known and the 'not yet known', already referred to in Chapter 2. The original Greek meaning of the word metaphor can be broken down into two root words, 'meta' and 'phora', which means simply to 'carry across' (Cox and Theilgaard, 1987, cited in Meekums, 2002: 22). Meekums laments the fact that little has been written about the importance of the movement metaphor in the DMP literature, however she draws effectively on a number of different sources, to illustrate why it is a 'central tool' in DMP as psychotherapy (Meekums, 2002: 24). I consider metaphor, especially the movement metaphor to be of central importance in dementia-care because non-verbal and embodied communications are less compromised by deterioration in cognitive function and thus more accessible as a route to communicating effectively with the person. Vital opportunities for understanding remain, especially in the later stages where verbal communications cannot be relied upon. As accuracy of meaning is lost, as words become scrambled and coherence appears to fade away, meaning can be attributed or re-attributed to the apparently meaning-less when understood from a metaphorical perspective. As Kitwood (1990: 40) argued, ' (i)nevitably, some of the language that we use to describe the subjective side of dementia is metaphorical: but as we all know, there's nothing wrong with that, for metaphor is one of our main resources whenever we want to convey meaning with vividness and colour'. Care staff will in all likelihood be challenged to make sense of these different ways of communicating as already discussed in Chapter 2, as without training and experientially based understanding I consider it is difficult for them to accept the movement metaphor as distinct from a literary or descriptive one. It is part of a relational and meaning-making process for

the care staff as well as for the DMP in improving the quality of dementia care, a central aim of this thesis.

The use of the movement metaphor is essential to the process of DMP and a brief example is used here to illustrate some key points. The illustration described here and others later in this thesis are based on a LMA carried out by Richard Haisma, a certified Laban Movement Analyst from New York. He kindly offered to analyse the VTR and the impact of the work on the patients, by way of deepening my own understanding of LMA in which I only have basic experience; and in response to my request for assistance in this regard from the American Dance Therapy Association website ([www.adta.org](http://www.adta.org)). Throughout the session, to be analysed and discussed in Chapter 7, Arthur sits on either one or both hands. Also from an LMA perspective, ‘(h)e sits in a frozen Homologous position, with shoulder tension and disconnections. He is virtually immobile throughout the entire session’ (Haisma, 2008: 14). His body posture was hunched and also described in LMA terms as having, ‘a Shape-flow Body-attitude of Narrowing, Shortening and Hollowing in the torso’ (p.14). I interpreted this body posture as a movement metaphor for ‘I’m not sure if I want to be here’. When, half-way through the session I asked if he’d like to hold a ribbon-stick, he quite emphatically indicated no by nodding his head left to right (Appendix A, 11.00am). On this evidence alone, I could have asked him if he wanted to leave or remain in the group. I chose to go with other evidence, which contra-indicated this. He had valued two previous sessions, and been more involved in session two than in this the third session. I considered he valued being a witness to the events and happenings in the session, to taking part and to listening carefully to what was going

on; even if he didn't actively want to participate much. Overall, and particularly on the 'embodied evidence', I decided that he was getting value from the session even if it was difficult to be specific and he had not asked to leave at any point. This was supported towards the end, when he spontaneously sang an extract from a hymn, 'Angels in the heights adore him'. This was a special moment for Arthur. While his sitting posture was a movement metaphor for, 'I don't want to be here', his spontaneous and moving singing at the end of the session touched something deep inside that was, I considered in the light of the available evidence, like a 'spiritual metaphor' for him, implying that something had triggered this important moment for him. I wondered if physical contact by way of his holding hands with a staff member immediately prior had triggered this singing, implying that the hand-holding too had acted as a movement metaphor for, 'I need to express this feeling in song now'.

The difficult circumstances surrounding the interpretations one makes as a psychotherapist, when working with people with dementia, mean that it is often difficult to gain corroboration from the person that the interpretation is accurate and that one is *not* coming to arbitrary conclusions. This is what makes working in this field psychotherapeutically challenging, because quite often one cannot be certain about the validity of the evidence used to interpret events, to make a decision or to take action. However, at the same time the psychotherapist must work in spite of these difficulties with whatever skills and techniques are available to them without using these difficulties as an excuse to resist interpretation. I consider it of central importance to the person with dementia, in relation to the movement metaphor, that access to a Dance Movement Psychotherapist presents the possibility for metaphoric

communications to have a better chance of being accurately interpreted and responded to, appropriate to their communication needs. Also it is necessary that the Dance Movement Psychotherapist is confident that the non-verbal and embodied evidence is consistent with that from other sources including the bio-medical and the multi-disciplinary team.

Without understanding of the movement metaphor and sensitivity towards its existence it is possible to dismiss it as irrelevant, peculiar or strange; by so doing one risks being unable to interpret the significance of the person's communication, by reason of being unfamiliar with the language of the 'movement metaphor', as a significant form of communication in its own right. One also runs the risk by way of being unable to make sense of the so-called 'non-sense', that communication breaks down and the therapeutic relationship is attenuated. Both are important points in the context of the Dance Movement Psychotherapist having specialist knowledge, which makes embodied communication and its meaning more understandable and vital in the context of the care process. If care-staff are not familiar with this specific form of communication then they risk missing out on being witness to some essential aspects of non-verbal communication. This highlights the need I think for care-staff to be provided with opportunities to learn these embodied practices and their significance, which I will refer to in Chapter 8 in more detail.

I shall now comment briefly on the function of the metaphor, especially the movement metaphor, in relation to people with mental-health problems. 'The movement metaphor in DMP facilitates a complex interplay between the embodied

experience of movement, associated sensori-motor ‘body’ memory, projected symbolism through the use of props, iconic imagery, affect and verbalisation’ (Meekums, 2002: 25). This complexity by way of incorporating a variety of different meanings is paralleled in relation to my own use of the visual and embodied metaphor a ‘bridge of understanding’ and how important it is to enable the person to build metaphorical and actual bridges between the known and the not-yet-known (see Chapter 2); it often comes by way of surprise with its immediacy, simplicity and profundity. The movement metaphor is in close contact with the psyche and,

(p)syche is the balancing mechanism of the personality; its function is to preserve the ecology of the soul. It is the part of oneself that is conscious of one’s belonging to the two worlds, one within and another without, and it struggles to integrate the two (Shorter, 1991: 4/5).

This definition by Shorter, a senior Jungian Analyst, outlines the nature of the psyche as a ‘balancing mechanism’, which functions to ‘preserve the ecology of the soul’. This is a powerful image suggesting that the psyche has an ‘ecology’ or world of its own, rather than simply a language or vocabulary, and that it struggles to ‘integrate the two’ worlds of inner and outer. The movement metaphor is therefore an attempt by the psyche to enable or facilitate integration between inner and outer, and therefore is of central importance in the therapeutic process (Meekums, 2002). Its function is also to suggest or point to alternative solutions to a given problem or difficulty the person is experiencing; especially since the metaphor alludes to a situation or problem rather than spelling it out directly. This indirectness has the dual

purpose of providing a degree of separation between the person, the difficulty and its resolution. It is helpful for the very fact that the person for whom the metaphor is intended, may have to work hard to discover its meaning. There is no general rule to say how it will work for the person, as each is unique, with his or her own movement vocabulary and movement signature. This premise of ‘working hard’ may need to be balanced against the person’s ability to do this, given their cognitive and emotional state, however in a general sense this search for meaning is of value because it empowers the person in the sense that it is a communicator of meaning. Indeed they may not have to work hard as the metaphor and the meaning may come in just the right form for them and at just the right time. For example, in Chapter 7 (Section 7.4.4) I describe how Gladys was constantly on the move in the session and could not sit still for any length of time. I wrestled with the meaning behind this constant movement that took place in the sagittal plane, with direct and sustained effort. Also,

She demonstrates little deviation from her Sagittal orientation Forward and rarely if ever moves side-to-side or into verticality. She has virtually no access to the Basic Action of Rotation, except slightly with her head, and consequently she moves as a single frozen unit when she changes direction in travelling (Haisma, 2008: 13).

I knew it was important that I did not interfere with her movement pattern by constantly inviting her to sit down, so instead I facilitated it. This made it difficult for me in terms of managing the group dynamics, as I always had to have my eye on and sensibility tuned to Gladys’s whereabouts in the room. She would move essentially in

straight lines, towards somebody in the group, or something that attracted her eye. If towards me, she would then make eye-contact attempt to kiss me on the cheek and move on. She repeated this behaviour with other staff, particularly the male staff. Haisma (2008) suggested that she might have been constantly on the go in her life, and her movement pattern was a metaphor for being able to maintain something she had always done; making contact with other people and then moving on.

Lastly, in this section I would refer to Phinney and Chesla (2003), who together in a contemporary phenomenological analysis concluded how people with dementia experienced their condition through the lived body. They identified three powerful and helpful movement metaphors to describe the symptoms of dementia as a result of their researches:

- 1) “Being slow” is about the body slowing down as taken-for-granted activities become halting and tentative; 2) “Being lost” is about being unable to find ones way in an unfamiliar world: and 3) “Being a blank” is about being in an empty world wherein meaningful habits and practices fall by the wayside (Phinney and Chesla, 2003: 283).

I have found these three metaphors very helpful in my clinical practice in relation to how people might be experiencing their condition from a lived and embodied perspective. They come from the researchers own study into how people live with this condition on a daily basis, and how it results for the person in a break up of what they describe as ‘bodily smooth flow’ (Phinney and Chesla, 2003: 288). The metaphors are psychologically powerful in the sense that they articulate new aspects

of dementia and its manifestation in the person that have not been presented before. While I recognise these movement metaphors in my own practice they can also be useful to the care-staff. However, they must not be used to label a person. They are useful metaphors; they are not labels. How might one work with a person who is exhibiting these behaviours in real time? What might one do with someone who feels ‘being lost’, or becoming lost, or even ‘lost in a fog’ as previously described in the poem by Doris Sarah Loxley (see Chapter 2.5). One could seek first of all to recognise this phenomenon, and then to help the person locate herself in space and in time. Working simply with and through the body is very helpful here, by using ‘Rhythmic Movement’ (Chaiklin and Schmais, 1986: 19), it is possible to help the person feel their body boundaries and connection with the ground through the feet. For the person ‘Being Slow’, the question of how to relate to them may involve the recognition that patience and acceptance of their condition is necessary; which may of course not be possible. For the person ‘Being a Blank’, a helpful and supportive approach may be to try and identify what might bring a connection or sense of meaning and purpose. What action, behaviour or quality of attention and intention in real-time might support an increase of well-being for the person?

I have wanted in this section to illustrate via Phinney and Chesla (2003) that whilst the movement metaphor can come directly from the person, this contemporary embodied perspective from researchers in the field represents a departure from the traditional mind/body dualism of bio-medical science, into the phenomenological and embodied and is therefore of particular significance.



#### **4.6 Dance Movement Psychotherapy and Symbolism**

I have referred previously to the importance of Symbolism in relation to the early work of Chace (4.2.1), who argued that through DMP, ‘(s)ome problems can be worked through on a purely symbolic level’ (Chaiklin and Schmais, 1986: 18) and need here to clarify its role and function in a contemporary context and in relation to people living with dementia. Symbolism is different from metaphor in a number of ways and yet of equal significance in how it contributes to the therapeutic relationship within DMP. Metaphor refers to the process of a ‘carry across’ of meaning from one realm to another, through body-posture and movement, through verbalising, through the use of props etc (Meekums, 2002). The ability to understand and use symbolism in clinically based DMP means that the Dance Movement Psychotherapist is aware that subtle and complex unconscious processes are at work, that have their roots in the early work of psychology pioneers Freud and Jung. They disagreed conceptually as to the meaning and importance of symbols in better understanding psychological processes and their importance in human development. The disagreement was so serious for both pioneers that, according to Samuels et al. (1986), it contributed to their now famous break-up. The debate, however, is still of contemporary importance and continues to this day. Freud, according to Jung, interpreted symbols as having *only* the role of ‘signs or symptoms of the subliminal processes’ (Jung, 1931: para. 105). Freud through his ground-breaking theories of ‘Free Association’ (Freud, 1976) and ‘Wish Fulfillment’ (Freud, 1976) argued that if in the process of psychoanalysis dream symbols perceived in dreams were followed quite logically and systematically wherever they led, then eventually they would lead

to the analysand revealing the unconscious causes of whatever ailed them. The ailment or problem could then be identified and labelled in psychoanalytic terms by the psychoanalyst, and in so doing Freud argued that the symptoms would disappear and the person would be cured. Symbols perceived in dreams and on the analyst's couch, according to Freud, always led to and came from the neurosis concerned. Detailed analysis for example of the dream and its specific contents were only relevant so far as they pointed to the particular condition or psychological ailment. By way of 'Free Association' (op.cit.1976) for example,

'My patients were pledged to communicate to me every idea or thought that occurred to them in connection with some particular subject; amongst other things they told me their dreams and so taught me that a dream can be inserted into the psychical chain that has to be traced backwards in the memory from a pathological idea (Freud, 1976: 174).

Jung however, while initially accepting and using these valuable methods himself, went on to pioneer an altogether different and wider interpretation of what he called, 'the true symbol'. Jung argued that, '(t)he true symbol differs essentially from this, and should be understood as an expression of an intuitive idea that cannot yet be formulated in any other or better way' (Jung, 1931: para. 105). This 'intuitive idea' however is not to be confused with its constituent parts and thus to have only 'an intellectual, expository and allegorical function' (Samuels et al., 1986: 144). Accordingly the symbol and the process by which it emerges, together with the way in which its meaning unfolds is both unique to the person and not as proposed by

Freud mainly emanating from a psychopathology. Jung writes: 'But to know and understand the psychic life-process of an individual's whole personality, it is important to realize that his dreams and their symbolic images have a much more important role to play' (Jung, 1964: 28/29). Jung went on to develop his own theories related to the importance of 'the true symbol' (op.cit.: 1931) within the process of 'Individuation' (Samuels et al: 1986), that was identified by Jung as an archetypal process unique to human growth and evolution. Jung was thus able to take Freud's initial pioneering work on dream interpretation (Freud, 1976), extending and developing it in new ways that made for a radically important contribution to understanding the fundamental importance of the symbol within analytical psychology. Jung's interpretation of the importance of symbolism, sits well within my own clinical practice of DMP.

According to Samuels et. al., (1986), 'Symbols express themselves in analogies. The symbolic process is an experience in *images and of images*' (p.145). Conceptually and theoretically, the idea that symbols express themselves 'in images and of images' (op.cit. 1986), is very significant and separates them from the concept of the 'movement metaphor' because:

1. They originate more archetypally.
2. They possess a psychic energy in direct proportion to the nature of the matter in question and its importance to the person.
3. They are unique to the individual, their life experience and process of 'Individuation' (op.cit. 1986).

4. The metaphor is a sign and is explicable whereas the symbol remains at some level inexplicable and is a pointing towards that which cannot be verbalised.

The symbol is therefore of profound significance in both psychoanalysis and psychotherapy and its purpose according to Samuels et al., (1986) is to 'play a psychological, mediatory and transitional role' (p.145) in the therapeutic process. Nevertheless, while both metaphor and symbol have their roots in the unconscious subliminal processes of the person, a true symbol within analytical psychology is an attempt by the psyche to express something for which no verbal concept yet exists and so it is the symbolic image or images that carry the meaning. The nature of one's psychic reality therefore plays a large part in separating the metaphor or sign from the symbol, 'Jung stresses that to be a symbol, rather than a sign, the analogy must point to some hitherto unknown bit of psychic reality' (Siegelman, 1990: 16).

I would illustrate the importance of the symbol and symbolism by giving the following example relating to my own recent clinical experience with a patient, here given the pseudonym Mrs E. I consider it an important example because it links the work of psychology pioneers, Freud (1976) and Jung (1931, 1964), DMP pioneers Chace (Chaiklin and Schmais, 1986) as previously discussed, with contemporary Dance Movement Psychotherapy practise. The example illustrates how profound this work and approach is in practise, in relation to symbolism and its relevance in the clinical situation. The psychotherapist may not be aware or necessarily in control of processes taking place at a deep personal and symbolic level. This example relates to experiences that took place post-discharge, to Mrs E who subsequently died of the

debilitating effects of the dementia condition and to me as her Dance Movement Psychotherapist.

I recently attended the funeral of a patient (Mrs E) with dementia syndrome who I had treated using DMP over a two-year period (see Coaten 2009, submitted for publication). The therapeutic relationship we had was a strong one, however once the person, Mrs E, had stopped attending the Day Centre where I worked, I lost touch with her, only discovering the date of her funeral a day or so beforehand. I attended her Quaker Funeral and was able to give Ministry about the importance of our two years of working together. I sat quietly afterwards in the garden of the crematorium, reflecting on our work and the psychological, emotional and spiritual legacy that I had been left with. During this process, while I was in a liminal state I had a numinous experience. I gently pulled two wafer-thin gold filigree threads about two inches long out of the ground, literally from under my feet. Suddenly and quite intuitively I realised that these objects were deeply symbolic of the legacy of dance that had become woven into both our lives. I immediately began to write up this experience, beginning at the crematorium. I first wrote in letterform to the daughter of Mrs E as a kind of eulogy to her life and legacy to me. I enclosed one of these gold threads in the letter as a gift to the family. I wrote that I hoped 'the dance', would continue to be woven as a thread into the life of their family as it would into the life of my own. I kept one of the threads and I intended for the family to keep the other. I later heard via letter from Mrs E's family that they had found my letter, and later my proposed paper, very consoling and important to them in their grieving process. The

letter had helped them come to terms with the loss through mental illness of such a vital and important member of their family.

This example of how the symbol emerged for me, in this instance post-therapy, could be described as of little relevance because it did not take place during the therapy itself but sometime afterwards. Logic would presuppose that the symbol emerge during clinical practice itself rather than afterwards. I have chosen this example deliberately because it illustrates that this symbolic experience was one which contained especial meaning and which came quite spontaneously. I was in control of neither the timing; the location or significance of it and its accompanying psychic energy took me quite by surprise. The symbol by way of the two gold threads was acting psychologically for me in my clinical role in relation to the work I had done with Mrs E and was acting in, 'a psychological, mediatory and transitional role' (Samuels et al., 1986: 145). The symbol was both the object (golden thread) and the image that it represented for me. The image was one of a very fine and beautiful thing that had presented itself while in this liminal space, enabling me to reflect posthumously on our therapeutic work together and the embodied nature of our dancing, moving and sharing together, prior to Mrs E's discharge from the service. The object was tiny and found in the ground under my feet, which was also symbolic because it related directly to the 'ground' on which we danced together and the earth in which these threads were buried. The objects found were very fragile and I considered them symbolic of the fragility and vulnerability expressed in the context of the therapeutic relationship given the increasing confusion of Mrs E over time. As with all references to the symbol and symbolic processes, their manifestation in a

Jungian sense is not to be taken too literally: ‘the symbol therefore is neither an alternative point of view nor a compensation *per se*. It attracts our attention to *another* position which, if appropriately understood, adds to the existing personality as well as resolving the conflict’ (Samuels et.al., 1986: 145). The symbol and its manifestation did not resolve a conflict, however it did add to my understanding and appreciation of the significance of our work together which was later evidenced in a letter to me from Mrs E’s husband:

I found it quite remarkable that you only knew (Mrs E) when she had dementia, yet she was able to respond in such a positive way to your involvement and you were able to discover how special she was to all of us (Coaten R, 2008 Personal Correspondence).

The symbol also mediated between Mrs E and me in the sense of its meaning and significance stemming from a past clinical situation, while subtly informing the nature of present and future clinical relationships. The symbol was multi-dimensional, dialectical and also another way of mediating and being a ‘bridge of understanding’ between conscious and non-conscious processes. Interestingly, this reference to attention being drawn to another position also echoes Best’s idea of being able to shift to alternative positions in her concept of ‘Interactional Shaping’ (Best, 2003) (see Chapter 3.6).

I consider that the symbol, its means and context of expression, in or outside of the therapy situation communicates diversity, widening and deepening the meaning and importance of the therapeutic process and relationship in the context of DMP. The

particular example given above concerning Mrs E, bears witness to the on-going and numinous nature of the symbolic processes involved that don't necessarily stop once the person is either outside the therapy room or as in this example, posthumously.

In conclusion, the work of the Dance Movement Psychotherapist in clinical supervision is to ensure that there is clarity, integrity and separation of clinical material between the therapist and the person undergoing therapy. The therapist is enabled to come to a clearer understanding of their impact on others and others on them, by way of analysing their assumptions and prejudices, especially those that appear to have a particular psychic energy. By this I mean an energy or resonance expressed in thoughts, feelings or images that will not go away, that requires further searching and re-searching to reveal its message. Clinical supervision is the process by which this searching and re-searching of clinical material happens and is vital in order to apply DMP safely, within a Code of Practice that also takes account of the policies and procedures of the NHS, or the employing organisation. Also noteworthy is that according to Miesen and Jones (1999), it is essential that carers ( read care-staff also) have a psychotherapeutic awareness in relation to concepts of the 'transference' and the 'counter-transference', supporting my own arguments presented earlier for the importance of carers and care-staff possessing psychotherapeutic awareness and understanding ( see section 4.5),

If carers are not aware of transference and counter-transference, problems can arise that compromise their professionalism. Insight into these processes gives



carers the chance to identify these conflicts, to deal with them and not to let them affect their work as carers (op.cit. 180).

This I think supports my own arguments for care-staff being enabled to come together to talk about matters and issues that have stirred particularly distressing feelings for them. This might involve for example working with people in care who are faecally incontinent or incontinent of urine or people who, for example, are distressed and who scream-out. Miesen and Jones also contribute here by arguing, ‘(w)hen carers discuss such themes with each other, they usually discover for themselves what their motivation to care is, and whether there are ‘extra roles’ involved’ (op.cit. p180). This argument for care-staff and carers to have more opportunities to share in what is now being known and described as ‘emotional-labour’ (Hunter and Smith, 2007) in dementia care is of great significance and will be discussed further in Chapter 8. Also important here is the reference to ‘extra roles’ meaning that through supervision, care-staff and carers can be helped to discover other aspects to the care process that had remained in the dark for them or in psychological terms, ‘unconscious’ or hidden. This supervision process and its importance in the context and quality of care also clearly separates the work of the DMP from that of the ‘devil-dancer’ (Frazier, 1976) as previously described.

#### **4.7 Dance Movement Psychotherapy in contemporary dementia care**

This section has the purpose of linking and describing relevant aspects of contemporary DMP practice reported in the literature with the themes and ideas presented in this chapter. This section ends by reflecting on the question of how DMP

with people living with dementia is different from DMP with other groups. Perhaps one of the most important aspects of it as an embodied practice is that it can, through the different techniques and ideas described in this chapter, offer new opportunities for improving communications between people with dementia and those who care for them. It is a main aim of this thesis to be able to offer and communicate different, non-verbal and embodied approaches for care-staff to improve and develop the quality of their communications. As reported in the dementia care literature,

The ability to communicate may be the best skill a caregiver can possess. Effectively and efficiently exchanging information and ideas permits us to be successful in our daily interactions – whether that be with the care team, the family, or our loved ones with Alzheimer’s disease (Haak, 2006: 77).

The ability to communicate effectively and well as referred to here is essential and Haak, as a care-giver rather than a Dance Movement Psychotherapist, goes on to describe particular approaches to improving non-verbal communications, by way of using body language and greater awareness of emotional content; what she describes as ‘affective prosody’ (op cit: 79). This refers to how pitch and tone and intonational range varies between communications that are joyful and those that are sorrowful; higher values are associated with joyful as opposed to sad communications, which include longer pauses that are decreased in pitch (Haak, 2006). A Dance Movement Psychotherapist would, in all likelihood, attempt to find ways to ‘tune in’ to the person, seeking to match body language, vocal pitch, tone and intonational range. They would also seek to be on eye-level with the person, rather than above or below

them, and they would aim for a genuine congruence between their intentions, their actions and their behaviours. For the person there must be no perceived inconsistencies in communications, verbal or non-verbal, that might threaten the possibility of relating 'effectively' and 'efficiently', as described above (Haak, 2006) and also emotionally, physically, spiritually and of course psychotherapeutically. These present particular challenges for any psychotherapeutically trained DMP, let alone for possibly untrained and unsupported care-staff, who in all likelihood have no opportunities for supervision in any of the complexities and difficulties surrounding communications and their care practice as previously reported above. Ward et al. (2006b: 24) reported evidence that people with dementia showed, 'the capacity to communicate by means that remain at best unnoticed and at worst considered part of the illness'. These were serious concerns as a result of their data analysis pointing out that care-staff were not reading the signs of the many different ways people were communicating with them; including the non-verbal, the embodied and the emotional. This evidence highlights the importance of the approaches used by the Dance Movement Psychotherapist in contemporary practice to people with dementia and to those who care for them as evidenced by Ward et.al (2006b), and Haak (2006). This view would I think, also be supported by amongst others, Chace (Chaiklin and Schmais, 1986), by Chodorow (1991), Goodill (2005), Hill (1999), Meekums (2002), Palo-Bengtsson (1998a, 1998b), Sandel (1995) and Shustik and Thompson (2002).

It is clear from the literature that DMP with people with dementia is a specialised area of practice. There are not many DMPs in clinical practice in this area and not a great deal of literature and studies in evidence. There are, for example, few

Randomised Controlled Trials in DMP with people with dementia, in part I think, because there are so many confounding variables in conducting research in this area in the first place and also very difficult to carry out. A recent systematic review of studies and case studies of 'creative therapy options for patients with dementia' (Schmitt and Frolich, 2007) in German, reported finding seven quantitative evaluated controlled studies and three qualitative evaluated studies since 1998 (op cit: 699). This is not many at all. The survey showed positive results like the 'improvement of interaction skills' (op cit: 699) and supported the use of creative therapies including DMP to help people accept, 'dementia as their illness and finally to cope with it' (op cit: 699).

Other studies concern the impact of social dancing and movement to music with people and their nursing staff (Palo-Bengtsson et.al, 1998a, 1998b, 2000). While not a Dance Movement Psychotherapist, Palo-Bengtsson and colleagues at the Karolinska Institute in Sweden have carried out pioneering studies with merit and importance to DMP. Her methods and data collection including the use of VTR within a phenomenological perspective inspired by Husserl's philosophy, point to the importance of social dancing as being both supportive to them and a way of helping keep and maintain abilities already present in the person (Palo-Bengtsson et. al., 1998a).

In a DMP study by Nyström and Lauritzen (2005), it was found that 'under conditions that allow for different modes of expression, the communication of the demented person can be found to be rich and varied in expression and content'

(p.297). These findings link well into my own arguments in this thesis for using a variety of different modes of expression with people with dementia and their care-staff. These different modes include the use of music, movement, dance, song, reminiscence, ritual and storytelling. All of these provide different ways for them to enter into the sensory and embodied nature of the DMP experience, and for the therapist to be sensitive and open to all the signals, however expressed, with a range of responses available. The range of creative expression also supports difference in quality range and depth of communication that are also potentially meaningful in a variety of ways. For example, a given gesture or movement may express a particular quality or emotion, triggered by a memory, by an image or even by a particular piece of music. A story or someone's memory may remind someone else of a song which could then be sung, enabling also the leadership of the group to be held by participating group members rather than by the therapist her or himself. Care-staff can also benefit from learning how to communicate more effectively, and in the process build better relationships, developing the quality of their work with those for whom they care. There is a richness and depth to this work that needs to be communicated to a wider public that is an important function for Dance Movement Psychotherapists working in this field.

What are the aspects of DMP that make it particularly special in relation to the treatment of people living with dementia? It is necessary to ask this question in order to identify how working as a Dance Movement Psychotherapist with this particular population is different from working with adults under sixty-five years for example. Does it present particular difficulties in clinical practice if people are cognitively

impaired? This means they may be unable, given their vulnerable state, to engage in in-depth dialogue with the psychotherapist about their difficulties psychological, physical, emotional or spiritual, which would certainly be easier given other client groups. I am drawing on both academic and clinical experience in attempting to answer this difficult question. Firstly, what is of profound importance is that I find myself working in the clinical situation with fragments of movement, action, dance, word, story, feeling, image, metaphor, symbol and behaviour. I have referred to the importance of these fragments before (Chapter 2), however in the context of what makes DMP different, the ability of the medium to trigger such a wide range of responses is particularly valuable. Where verbal and cognitive ability are compromised, then it is essential that any available communication routes be used in order to meet the person just how they need to be met and DMP provides these routes.

Often I am not in a position to know for sure the meaning or significance of the gesture, the word, the feeling or the memory triggered by a piece of music or by a prop. I have on occasion to make an educated guess, intuitively and instinctively, with little time to stop and think about what has just occurred, as I am working in the moment with the person. I aim as far as possible to be attentive to how these fragments coalesce for the person, both during a session and over a course of sessions. Meaning gradually coalesces, metaphorically speaking, similar to how a mosaic is formed from fragments of ceramic tile, or how threads, metaphorically speaking can be woven together via both warp and weft (a theme I return again to in Chapter 8). I am attempting to build and sustain a relationship on which something

new can be built, or something recovered and remembered, which was perhaps lost or forgotten, providing support and help for the person and their identity, even if it is not possible to ‘cure’ them of dementia syndrome. It is fundamentally about being in relationship with the person, able to relate to and witness the expression of meaning or of whatever is important to them at the time; this means them somehow inter-subjectively knowing, or intuiting that you know this too - and in that shared moment of coming to know, identity at a profound level is somehow affirmed for both people.

There is a comparison I can make here, to illustrate this approach in a slightly different way, by drawing on the work of a pioneering Jungian analyst who was both a colleague and contemporary of C.G. Jung. He says of the psychotherapeutic process, ‘Nor should we be trying to understand what the patient has expressed primarily in order to “cure” him with it, but rather to share in his life and so to share with him the experience of being human. This is not therapy but the basis of therapy’ (Fierz, 1991: 186). I consider this an important statement from one of the early pioneers of Jungian psychoanalysis and psychotherapy, and particularly relevant in a clinical sense to answering this question. The argument that Fierz makes, about not trying to understand the patient or the person in order to cure them, is particularly relevant in dementia care because Alzheimer’s disease or any of the other dementia syndromes remain incurable. This fact will in all likelihood remain so for the foreseeable future, in spite of current advances in medical science, for example in relation to vaccine development (as previously described in Chapter 3) to prevent the slow-down of the growth of plaques and tangles.

This argument also means that simply by being with the 'other', accompanying them on their journey without the unconscious need to 'cure' or affect change, is of particular importance. This as applied by the Dance Movement Psychotherapist in different, embodied and relational ways, makes the process and practise of DMP with people with dementia quite unique, because we have at our disposal a wider range of therapeutic skills, abilities and techniques that give us access to people compromised in these different ways. In being able to meet the person where they need to be met in these different ways, it also means being able, 'to share in (his) life and so to share with (him) the experience of being human' (Fierz, 1991: 186). This implies helping the person perceive more about themselves, helping locate them in the lived moment in the lived body and helping them accept the reality of who they are now and who they are becoming.

The Dance Movement Psychotherapist is also trained and experienced in paying attention to that which is being expressed through the body un-consciously. People with dementia are experiencing profound loss including the emotions of grief, sadness, shame and existential suffering and these become embodied and expressed rather than necessarily cognitively experienced (Oyebode, 2008). They may have lost a home, lost their health and sense of well-being, lost a co-habiting spouse or partner, lost or losing their identity and all these may present unconsciously and in embodied ways in the session. Sadness, grief and loss are expressed non-verbally in many ways and one of the most common examples can be through an observed inertia in the group dynamics. People with dementia may be reluctant to express themselves verbally on any subject for *fear* that their words may be spoken in the wrong order,



their meaning misconstrued or misheard by someone. They may be reluctant to participate in movement-based activities for fear that they may become exhausted or that they may look silly or awkward in performing a task in front of others. They may have lost confidence in themselves and together these may have contributed to what Phinney and Chesla (2003: 283) have described previously as 'Being Slow', 'Being Lost' and 'Being a Blank'. Eyes may also fill up with tears as a memory returns or they have insight into their loss and resulting grief. What is so important in relation to the function and role of the Dance Movement Psychotherapist is that they are able to pick up and respond to these subtle embodied and often metaphoric cues and change the course of the session in response to them. It could mean not focussing on one person who is feeling uncommunicative with the focus moving to someone else, while the Dance Movement Psychotherapist has time to reflect on what action or behaviour might reduce and/or raise well-being instead. The Dance Movement Psychotherapist might discover that they like a particular piece of music or song and by playing or singing it, give back to the person something they consider of value, which in turn supports identity, social interaction, reducing ill-being and valuable also to others. In this subtle way relationships are built together between psychotherapist and group, that can help overcome loneliness and fear, by enabling expression of it as people learn and gradually trust that however they are feeling it is accepted and valued. Acceptance and valuing of the person is also at the heart of Person-Centred Care (Kitwood and Bredin, 1992a: 274), which will be discussed next in Chapter 5 as both DMP and Person-Centred Care are closely related in these embodied and inter-subjective ways.

## **Chapter 5 Person-Centred Care**

### **5.1 Introduction**

Person-Centred Care (PCC) is a term used to describe a now nationally recognised and important contemporary care framework for the support of all older people, especially those living with dementia and those who care for them in the UK. It is a guiding set of values and principles now written into many health strategies and policy documents, protocols and job descriptions across the care sector and is a frequently used term (Adams, 2005, Alzheimer's Society 2001, Brooker, 2007, Dept. of Health, 2001a, 2001b, Kitwood and Bredin, 1992c, Morton, 2000). It is within this overall care framework that DMP takes place in the NHS, helping create and support a more enlightened, humane and sensory-oriented care culture as previously posited in Chapter 2. PCC now represents a vitally important factor and context in which contemporary dementia care takes place. Proper discussion and analysis is necessary of what it means in theory and practice, also how important it is in the context of contemporary service provision and future development. We can better understand in this analysis, for example, how quite major changes have taken place over the last twenty odd years in the way the quality of dementia care can be framed, assessed and improved.

This Chapter will attempt to repeat the approach used in Chapter 4 investigating DMP; first of all by looking closely at roots and origins of PCC and working up to the present day in relation to contemporary theory and practice highlighting important issues. Difficulties surrounding the widespread implementation and development of

PCC across the care sector are also briefly referred to here. Knowledge about the spread and take-up of PCC also has an impact on DMP and vice-versa in relation to a developing quality of service provision. For example, care-staff experience many pressures on them to carry out their duties within the context of PCC, while trying to adhere to the values, principles and practices of this approach with very little, if any, training. DMP by way of ‘Creative Care’ discussed in detail in Chapter 8 can contribute to alleviating this situation. This chapter will discuss in more detail the underlying values and principles of PCC, such as ‘Personhood’ (Kitwood and Bredin, 1992a: 274) (see below section 5.3.1) and the impact of the environment and the culture of care on people living with dementia. The chapter will also refer in some detail to the development of a methodology called ‘Dementia Care Mapping’ (Kitwood and Bredin, 1992b), a major element in the context of this study investigating the impact of DMP on older people in a care setting living with dementia.

## **5.2 Origins of Person-Centred Care**

Person-Centred Care (PCC) developed in relation to the work of Brooker (1995), Cheston and Bender (1999), Goldsmith (1996), Kitwood and Bredin (1992a, 1992b), Killick (1997a, 1997b), Killick and Allan (1999), Kitwood (1997a), Marshall (1998), Perrin (1997), Rader (1995 cited in Brooker 2004), Sabat (2001, cited in Brooker, 2004), Stokes and Goudie (1990), Wilkinson (1993) and others in the 1980s and 1990s. It is helpful however to identify earlier sources that also influenced its later development. This process of returning to the theoretical and practical work of earlier

pioneers whether in DMP or PCC is an important one. I have previously discussed the roots of DMP in Chapter 4 and here in the case of PCC I am aiming to deepen and broaden understanding about how theory and practice, albeit in different disciplines, evolves and develops over time. Insights gained by way of this analysis help in ‘building bridges of understanding’, between past, present and future. The interdisciplinary and the inter-subjective realms remain key themes throughout this thesis, with its overall commitment to better understanding the lived experience of people living with dementia and those who care for them, going by way of theory and practice. In the following passage Kitwood (1997a), identifies an important factor in better understanding theory, ‘...(i)t is not that theory is important in itself, but that it can challenge popular misconceptions; and it helps to generate sensitivity to areas of need, giving caring actions a clearer direction’ (p.15). It is by way of ‘giving caring actions a clearer direction’, by investigating theoretical roots and origins that I seek to identify the importance of the work of earlier pioneers in the context of PCC.

Writing in his last book, Kitwood (1997a) described the connections he made between the Rogerian Person-Centred Approach and what he was later to call Person-Centred Care (Kitwood and Bredin, 1992c). Kitwood was profoundly influenced by the status Rogers placed on the importance of communications taking place within the warmth, the congruence and valuing of the ‘client’ (see below). The Rogerian Person-Centred Approach therefore plays a very important role in the origins of Person-Centred Care, partly because of the psychotherapeutic weight Kitwood hoped his approach could carry and also because of the similarity of chosen name, thus warranting further investigation and discussion here. What follows is a brief resumé

of some of the constituent parts of Rogerian Therapy in order to better understand the values underlying Person-Centred Care.

### **5.2.1 Rogerian Person-Centred Therapy**

Carl Rogers was Professor of Psychology and Director of Counselling Services for the University of Chicago in the USA, setting up his own counselling centre at the University in 1945 for what he described as ‘Client-Centred Therapy’ (Rogers, 1984). The basis of Rogers’ pioneering approach was a gradually formed and tested hypothesis that the individual has great potential and inner resources for self-understanding and knowledge that can be used to great effect in the therapeutic process, and in the cause of self-development, counselling and psychotherapy. These inner resources and self-understandings however, can only be properly accessed and used well within the context of a clearly defined psychological climate and what Rogers described as ‘the conditions of psychological growth’ (Rogers, 2004: 60). Emphasis was placed therefore on the development of a relationship between client and counsellor/therapist based on three key values:

1) ‘Congruence’ (Rogers, 2004: 62) refers to the necessity for qualities of genuineness and authenticity on the part of therapist and client and the relationship between them. The therapist aims to discover through the therapeutic relationship matters that according to Rogers are both ‘Congruent’ and also ‘Incongruent’ (op.cit. 62), and the extent to which the client is able to live true to who they are as a person without ‘distortion’, ‘denial’ or ‘incongruence’.

2) Acceptance in the form of ‘unconditional positive regard’ (Rogers, 2004: 62), meaning that the ‘client’ as distinct from the ‘patient’ is valued in ‘a total rather than a conditional way’ (op.cit.: 62). This unconditional acceptance also extends to the client’s present moment feelings and attitudes regardless of how much they may feel that these have changed over time.

3) ‘Empathic understanding’ means that the therapist is able to empathise with the ‘other’ to the extent of being able to perceive and articulate back to the person thoughts and feelings as if they were that person.

All three psychological conditions described above link well with Kitwood and Bredin’s (1992c) later work on what they were to call a ‘Person-Centred Approach’ in dementia care. The following quotation from Rogers hints at a salient psychological direction that Kitwood and Bredin would later take: ‘I can only try to live by *my* interpretation of the current meaning of *my* experience, and try to give others the permission and freedom to develop their own inward freedom and thus their own meaningful interpretation of their own experience’ (Rogers, 2004: 27). I understand from this the importance of valuing my own lived experience as researcher/practitioner and what I have discovered along the way. Transposed into dementia care, these insights represent a psychologically oriented challenge to all care staff to become more aware of the ‘meaning’ they attach to their own experiences in the care setting. The claim is that this will better equip them to give greater credence to the value and meaningful interpretation of the lived experience of those with whom they work. Implicit here is a tacit knowing that for care-staff, the

acquisition of knowledge, skill and experience in the dementia care relationship has to be matched by what has been described as ‘emotional intelligence’ (Damasio, 2000). This means that care-staff must clearly demonstrate their awareness of the lived experience of dementia, as expressed emotionally, psychologically and be able to apply these insights practically in the care setting. Some work has been done in this area (Cheston and Bender, 1999), however in 2008 there is growing interest in relation to what is being described as emotional-labour for carers and for care-staff in care settings (Sheard, 2009 in press) and for emotional-labour in nursing generally (Hunter and Smith, 2007). This means that with a growing awareness of emotional expression, emotional literacy and emotional-labour, the true psychological conditions within which care-staff work can be brought to the fore in the debate about how best to support, train and nurture staff in this extremely important role.

Taking this a step further, care-staff have to better appreciate their own care experiences first, and the meanings underlying them, before they can really be effective at appreciating and giving value to the experiences of others, especially those living with dementia. Being emotionally congruent thus makes it easier for staff to elicit meaning from the care situations they find themselves in. This process is mirrored by the journey a person takes to become a Dance Movement Psychotherapist. The acquisition of knowledge, skills, training, personal therapy and clinical supervision is first undertaken by ‘Self’. The elements of the training are designed to combine, thus enabling the person to better appreciate their own strengths and weaknesses, their own feelings and the meanings they attach to them. Eventually, having worked on ‘Self’ to a high degree, the psychotherapist is then better able to

develop an emotionally congruent and psychotherapeutic relationship with the client or 'other', that can develop and evolve over time.

The use of the term 'client' by Rogers implied that clients were self-responsible and represented an important shift away from use of the term 'patient'. Rogers was keen to stress the following:

... it is the *client* who knows what hurts, what directions to go, what problems are crucial, what experiences have been deeply buried. It began to occur to me that unless I had a need to demonstrate my own cleverness and learning, I would do better to rely upon the client for the direction of movement in the process (Rogers, 2004: 11/12).

Here Rogers is clearly stating the value he attributes to reliance on the 'client' to set direction and movement in the process of therapy. For the time during which these ideas were presented in books, papers and lectures in the 1940s through to the 1960s, they presented a radical challenge to psychiatry and they were not well received at the time by the psychiatric establishment generally. This response was hardly surprising given the fact that psychiatrists trained in the medical model would find it difficult to appreciate and accept a humanistic approach, grounded in the context of the 'patient' setting 'direction of movement', in the context of treatment.

Two of Rogers' principles need highlighting in relation to the later development of PCC. One is the assumption of the uniqueness of the human being at all times; and the second is a reliance on the client for the ability to have a sense of 'direction' in the



process. The therapist therefore needs to be able to get inside the client's world, while totally accepting the importance of being congruent and genuine and having an empathic understanding towards the **other**. Kitwood at a later date went on to develop the idea that the role of the therapist in Rogerian Therapy can be transposed onto the role of the care-staff in the context of dementia care. In other words, care-staff need to possess, and be able to use effectively and well, a *psychologically* framed understanding, being emotionally and psychologically congruent; recognising the uniqueness of the individual person living with dementia, in the context of what he and his colleague were also to describe as 'Personhood' (Kitwood and Bredin, 1992a: 274). Brooker too emphasises the importance of the psychological in her own analysis of PCC,

'....most poor quality care and neglect that is experienced by people living with dementia is psychological rather than physical. Incomplete assessments, no one contacting you when they promised, feeling deceived, the withholding of information, the over-prescribing of drugs that you don't need and the under-prescribing of ones you do' (Brooker, 2007: 32).

The question of how to effect change while implementing these psychological insights in the care setting is another narrative and something I will attempt in Chapter 8.

### **5.2.2 Rogers on Growth**

Rogers argued that the client could be helped to value the importance of personal growth through a gradual transition away from behaviours and actions related, for example, to maintaining the expectations of others, or from façades and keeping up appearances including externally imposed obligations. Growth could be seen by way of valuing honesty in relation to self and others, also by way of a growing capacity to direct one's own life and to valuing experiences and the growth process supporting the person generally. I think Rogers was seeking to identify what, in the inner-life of the person, was getting in the way of them being as alive to the present moment without misrepresenting or denying perceptions of their present reality. Kitwood too sought answers to the question, 'What in the environment or culture of care might be preventing the full realisation of "personhood"? (op.cit. 274)'.

In this brief analysis and reflection on the work of Rogers, it is not difficult to see how these values and principles could be transposed into a dementia care setting with people living with dementia. It is perfectly possible to trace a 'through-line' that links the two pioneers together by way of this respect for, and understanding about, the ability the individual has for growth and development in their life. This respect for and valuing of the person continues in the contemporary literature about PCC, especially in relation to the provision of care services, '...care providers need to make the valuing of the quality of lives of people with dementia their explicit business if they are serious about providing person-centred care' (Brooker, 2007: 16). PCC presents the possibility for learning, growth and change even in late stage dementia

by focusing on the person, their capabilities and resources in spite of a whole range of disabling factors, including neurological impairment. Here philosophically and psychologically lie great challenges to the implementation of these values and principles in contemporary care practice, because the nature of the person with dementia's lived experience of care is so closely tied into the lived experience of the providers of that care. If care-staff are not working from a Person-Centred value-base and the organisation itself is not geared up to provide it, then the quality of that care and the quality of life of those receiving it will inevitably be the poorer for it.

### **5.2.3 Other influences on the development of Person-Centred Care**

There were other significant influences on Kitwood: 'I have found myself becoming, at different times, a disciple of Freud, Klein, Jung, Berne, Rogers, Perls and several others in my own attempts to make sense of the dementing experience so far as it has been communicated to me' (Kitwood, 1990: 48). This quotation reflects the breadth and scale of Kitwood's growing interest in the care of people with dementia as an academic psychologist, informed also by his previous studies in the Natural Sciences at Cambridge University and by his training to become a priest at Theological College. In the same seminal paper he also questions why traditional old age psychiatrists, psychoanalysts and psychotherapists from Freud onwards had been dismissive of the idea that psychotherapy with people living with dementia was possible. This was because they saw "“real psychotherapy”, which aims at bringing about profound and enduring changes within persons' (Kitwood, 1990: 42), as not possible with people whose 'ego-strength' was poor and whose minds compromised

by the condition. Sufficient ‘ego strength’ and intact intellectual processing functions had been seen previously as essential pre-requisites for psychotherapy.

He went on to explore these suppositions in detail in relation to what he described as his ‘psychobiographical data’ (op.cit. 42) and detailed observations built up over a number of years, from 1985 onwards, regarding what life was really like for those living with dementia in care-home environments. Whilst Kitwood admitted there were methodological flaws in his ‘psychobiographical data’, also recognised by others studying them in detail (Adams, 2005), he remained confident that as a body of work they stood up to scrutiny. Kitwood remained surprised by the fact that previously there had been no literature about, or researches on, the *subjective* experience of the person living with dementia. What was it really like to live with a ‘dementing process’ (Kitwood, 1990: 44) on a daily basis? It was as a result of Kitwood and Bredin’s (1992a, 1992b, 1992c) pioneering observational studies, the contribution of other colleagues in the field, for example, Goldsmith (1996) and Cheston and Bender (1999) and the later development of the observational methodology called ‘Dementia Care Mapping’ (see below section 5.3.2) that a gradual understanding and awareness emerged of the psychological conditions present for people experiencing a dementia condition. These conditions are well described here:

The most appropriate starting point for any psychological considerations of people with dementia and the services that they need should be the subjective experience of people with dementia. This is characterised by both the

experience of loss (of social roles and relationships as well as of neurological functioning) and the threat of further losses to come, and results in a range of emotions including grief, depression, anxiety, despair and terror (Cheston and Bender, 1999: 147).

This powerful description of the psychological conditions present, especially in relation to loss, underpin the strength of Kitwood's arguments; while psychotherapeutically ego-strength and cognition may be profoundly affected, as discussed above, the subjective experience of dementia care can be profoundly changed for the better by way of the application of psychotherapeutic insight. If not, then the conditions remain for the 'Malignant Social Psychology' (Kitwood, 1990: 45, described below in section 5.3.1) to persist with little or no positive change.

I refer the reader back to Chapter 2 at this point, which stressed the importance of **subjectivity**, **inter-subjectivity** and also **reflexivity** within an anthropological perspective in getting to know the 'other'; as with getting to know about the lives of indigenous people in their own environments and cultures (Schultz and Lavenda, 1990: 54-55). Here Kitwood, in the context of dementia care, has embarked on a form of anthropological and ethnographic study (as well as psychotherapeutic) in relation to his interest and detailed observations. His 'psychobiographical data' (op.cit. 42) involved detailed interest in the subjective experience of the person living with dementia, coupled with the inter-subjectivity of their relations with others, including carers and care-staff in the care environment. It is noteworthy that the roots of the separate and distinct fields of Dance Movement Psychotherapy, Anthropology,

Ethnography, Rogerian Therapy and Person-Centred Care can be linked by the work of pioneers in these respective fields, who have returned to earlier ideas and arguments, in order to better understand the human condition, ‘building bridges of understanding’ in the process. The daunting task of caring for growing numbers of cognitively and existentially impaired people living with dementia in future, demands that care-staff, carers and clinicians are best equipped for that task, drawing on whatever influences, like Kitwood and Bredin, can help widen and deepen the context within which the care process happens.

Lastly, in this section I draw attention to the existential philosopher and mystic Martin Buber, who was cited by both Rogers and Kitwood as being influential to them. Buber describes the importance of meeting the ‘other’ from two differing perspectives: one was from an ‘I/It’ standpoint where there is distance, lack of warmth and congruence in the relationship; the other is from an ‘I/Thou’ perspective. An ‘I/Thou’ relationship means, according to Buber, a sense of ‘confirming the other’, where ‘confirming means...accepting the whole potentiality of the other...I can recognize in him (sic), know in him, the person he has been...*created* to become ...I confirm him in myself, and then in him, in relation to this potentiality that...can now be developed, can evolve’ (Buber, 1937, cited in Rogers, 2004: 55). The importance of the ‘I/Thou’ position in the context of the therapeutic relationship is key to better understanding the roots of both Rogers’ and Kitwood’s need for seeing and valuing the ‘other’ in relation to self. The concept of a deep valuing of the ‘other’ is deeply embedded in Kitwood’s philosophy and approach in PCC. This is evident in how it manifests in contemporary dementia care practice and also how it doesn’t manifest or

it is particularly challenging for it to manifest, for a number of reasons I will discuss below (see section 5.3.1).

### **5.3 Kitwood and Person-Centred Care**

In the late 1980s and early 1990s, Kitwood, a clinical psychologist at the University of Bradford, along with his colleague Bredin, began to study older people in residential care homes. They wondered why the care processes and organisational cultures they witnessed in the homes produced such grim findings in relation to the lack of respect both for the person with dementia and the care-staff. ‘Organizational structure, the type of training and the specification of the role of care-worker all tend to require people to operate, very largely, from a ‘frozen’ state’ (Kitwood and Bredin, 1992a: 286). Kitwood and Bredin began research in this area and looked at the detailed experience of the person with dementia in residential care homes, on an hour-by-hour and minute-by-minute basis. They wanted to know what the *experience* of care was like from the perspective of the person receiving it in order to have a better understanding of the impact on the person. They witnessed many processes that were undermining and began to log, categorise and analyse them. From this analysis, they were able to comment from a much more informed perspective. They argued that people with dementia, while subject to whatever neurological changes were taking place in the brain, could also be the victims of a prevailing care-home culture that reinforced values, attitudes and care practices that manifested in a ‘malignant social psychology’ (Kitwood 1990: 45).

### **5.3.1 Malignant Social Psychology**

Kitwood described a ‘Malignant Social Psychology’ (MSP) as the psychology of relationship that included, ‘a set of deficits, damages and problem-behaviours, awaiting systematic assessment and careful management’ (Kitwood, 1993: 16). The term ‘malignant’ Kitwood used to describe occurrences in the life of the care home resident that were, ‘ very harmful, symptomatic of a care environment that is deeply damaging to personhood, possibly even undermining physical well-being’ (Kitwood, 1997a: 46). Kitwood used a powerful image in describing what he meant by this phrase, drawing the ‘malignant’ aspects of neurological deterioration, social psychology and poor care practices in a diagram that described an ever-decreasing spiral; a spiral that wound in on itself, where each negative experience compounded that of the previous one (Kitwood, 1997a: 52). Throughout the narrative of the case of ‘Margaret’, for example, the subject of this malignant spiral in the diagram, her unique ‘Personhood’ was undermined in the context of being ‘outpaced, invalidated, objectified, disempowered and labelled’ (Kitwood, 1997a: 52), leading to her eventual death.

Within the prevailing bio-medical aetiology and culture of ‘reductionist’ assessment and management, Kitwood and Bredin, amongst others, recognised that people with dementia were in danger of becoming lost; they had as people become de-valued and objects to which things were done. Kitwood was keen to stress that the operation of this ‘MSP’ (op.cit.: 45) was not intentionally malicious on the part of the care-staff; however the effects and predominance of what he regarded as the ‘old’ culture of care, was very evident across the sector. The explicit contrasting of the ‘old’ versus



the ‘new’ culture of care was of growing importance in this care sector from the mid 1990s on (Kitwood and Benson, 1995).

The following is an attempt to clearly identify and summarise the main contributing factors to the creation of a ‘Malignant Social Psychology’ that Kitwood and Bredin found so prevalent in their researches. The factors described and summarised below, combined in the context of the care environment, to make it very difficult to change care practices for the better by tackling one or more of them in isolation. Factors described below include: poor funding and two-tier funding policies; poor staff training; the lack of a theory of the process of care; prevailing attitudes across the sector; task-oriented approaches to care; prevailing attitudes to care and evidence for high states of observed ill-being. I have placed them within structural, organisational and operational contexts all of which contribute to the creation and maintenance of ‘MSP’. I have also attempted within this analysis, to address the problem of the complexity of how these issues each relate to and influence the other within a complex living system. Specifically, how to delineate issues that were recognised by Kitwood and Bredin in the mid-1980s as being relevant to their observations, from those still relevant today? To that end I have, somewhat artificially, sub-divided each category into the situation that existed at the time Kitwood and Bredin were writing (Past) and the situation that exists today (Present):

Factor 1 (**structural and organisational**) – Poor-funding.

**Past** - The socio-economic climate within which the care of older people was taking place resulted in not enough value being placed on the importance of,

and necessity for, high quality care provided by highly trained staff working with the most vulnerable and needy members of society.

**Present** – The situation today is hardly different. Many residential homes have had to close in response to the development of regulatory, including health and safety frameworks that have added a burden of additional costs on already struggling care homes. For those that have survived, including the larger care home groups, two-tier funding policies have radically changed Care-Home funding. Local Authority funding priorities in England, Wales and Scotland are contributing to the growth of ‘Specialist Dementia Day Care Units’ resulting in the segregating of dementia care services. Continuation of poor funding at national level and more recently the creation of a two-tier funding system, have seen major changes taking place in the sector generally. In 2008, small and large care home providers offering ‘Specialist Dementia Care Units’, for people diagnosed with dementia or EMI (Elderly Mentally Infirm) received higher fees for doing so from local authorities. This stimulus has resulted in many care homes moving to convert parts of their old buildings, or to create new ones for this purpose, thus accessing higher per-capita fees. Burton (2008), argues these economically driven incentives are of serious concern to all in the dementia sector, resulting in the *segregation* of people with dementia into the ‘specialist unit’, downgrading the generalist home while rewarding the ‘specialist’ one. Also according to Burton there is, ‘little evidence that specialist units and whole homes, particularly nursing homes, give better care and a happier life to most people with dementia. Indeed, my own observation of such homes is that many of them are pretty

poor' (op.cit.: 34). Results of the funding slant towards the 'specialist unit' has also, according to Burton, reached a point where care policies and practices in these units are 'completely at odds with the standards (National Minimum Standards) themselves' (op.cit.: 35) and in spite of these recent developments, many people with dementia remain cared for in the generalist homes. Burton also argues that the care of all older people and not *just those* with dementia, should be carried out in person-centred ways, and I wholeheartedly agree with his argument: 'it is widely recognised that up to two-thirds of all care home residents have some degree of dementia. So, why do we have this ignorant, superior and malignant division between specialised 'dementia care' and all other care?' (op.cit. p34).

Factor 2 (**structural/organisational/operational**) – Poor staff training.

**Past** - Little or no care staff training was being provided across the whole sector to address the special nature of care requirements for people with dementia. This was a real problem and as the National Service Framework (NSF) document says, in terms of workforce development, 'Staff do not necessarily intend to behave in a discriminatory fashion, but lack of skills and lack of confidence in working with older people can lead to behaviour which is perceived as discriminatory' (Dept of Health, 2001a: 21).

**Present** – The situation today with the lack of staff training generally is hardly different, however it is at last being taken seriously as the latest thinking from the Department of Health is that, 'The need for improved

training runs across all of the themes in this draft National Dementia Strategy...professionals are often unwilling to adapt their practices to make them work for people with dementia' (Dept. of Health, 2008: 30). The proposals contained in the draft document also identify 'the training of all health and social care staff in the sector as of central importance' (op.cit. 30). This represents what could be described as a sea-change in thinking from the UK's Department of Health, however according to Sheard another major issue in the provision of care-staff training is that it remains focused on skills and competency-based frameworks; on 'doing to', rather than on 'being with', resulting in 'failure to see person-centredness is a life philosophy not an approach about care alone' (Sheard, 2008, personal communication). This also means that training, in order for it to contribute effectively to practice change, needs to be focused on changing attitudes, values and belief systems, within person-centred leadership, management and organisational structures that work seamlessly together.

**Factor 3 (structural/organisational/operational)** – The lack of a theory of the process of care.

**Past** - Without a theory of the process of care for people with dementia standards could not be set or agreed to which institutions could be held to account (Kitwood and Bredin, 1992a). This presented a fundamental problem that Kitwood and colleagues worked to overcome by being better able to analyse and understand the care experience as it was lived.

**Present** - This is being remedied in relation to the National Service Framework and other programmes initiated by the Department of Health (Dept. of Health, 2001a, 2001b, 2007) and in 2008 their consultative process on the creation of a National Dementia Care Strategy (Dept of Health, 2008). Also, the Commission for Social Care Inspection (CSCI) has recently developed in association with the Bradford Dementia Group (BDG) an inspection tool called the 'Short Observational Framework for Inspection' (SOFI), 'that allows inspectors to go below the surface of routine care practice' (Dept of Health 2008: 48), by focusing on their qualitative observations of it. To that end, there is evidence in West Yorkshire of Care Inspectors receiving training in 2008 in Dementia Care Mapping from the BDG and its affiliates, in recognition of the fact that if inspectors are to be best equipped to recognise PCC when they see it, then training in it is a necessary pre-requisite. This is a welcome sign at this time for evidence of change in the inspection regime.

Factor 4 (**attitudinal**) – Prevailing attitudes across the sector.

**Past** - prevailing attitudes in dementia care across the sector regarded 'challenging behaviour' as a part of the disease process itself, in line with traditional bio-medical approaches, rather than as meaningful attempts to communicate needs and wants. This resulted in important attempts to communicate being ignored by the care-staff, and people with dementia labelled as unable to communicate as a result of the disease. Labelling can

result in people being very subtly ignored both verbally and non-verbally by care-staff. Also attention can be directed by care-staff to those with ostensibly the most challenging needs, ignoring those whose behaviours and communications may not be as overtly demanding, but needy in other more emotional and less obvious ways.

**Present** - One of the most important assumptions within PCC being the idea that all communication has meaning, however expressed, and this argument was pioneered by Sabat and Harré (1994) among others. ‘It may be that confusion is demonstrated, not by the person with dementia, but by those who do not hear the meanings being conveyed and, hence, deny the dementia sufferer’s standing as a semiotic subject’ (Sabat and Harré 1994, cited in Hughes et. al., 2006: 147). Stressors on the person with dementia increase as a result of these infantilising and disempowering attitudes; depriving people of their innate humanity resulting in this ‘malignant’ spiral in behaviour, well-being and attitudes to self and others. Also noteworthy is that within the two-tier funding system described in Factor 2 above, people with dementia in the generalist homes can find themselves referred to the so-called ‘specialist’ ones’. An inappropriate referral can take place if the extent of their ‘challenging behaviours’ becomes too much for other residents and staff to bear (Macdonald and Denning, 2002), resulting in more distress to the person through upheaval, lack of consistency in care, and changing people, routines and care environments.

Factor 5 (**organisational**) – Problem of a ‘task-oriented’ approach to care.

**Past** – A ‘task-oriented’ approach occurs when the care routines and procedures take precedence over the individual needs of the person. The daily routines would be set around the needs of the organisation rather than the needs of the individual. If individual needs were not being met, then it was likely that observed ‘ill-being’ and challenging behaviours would increase, well-being decrease and the quality of life of the person decrease in consequence. Kitwood described, and then reflected on a very disturbing vignette of care, in a care home written by an experienced member of the care team reflecting back on her experience in 1984. It involved several older people being abused both physically and emotionally while sat on commodes,

‘When we consider that horrifying episodes of this kind were typical, not exceptional within the ‘old culture of care’, it is impossible to hold the view that all of the personal deterioration associated with dementia comes about as a result of a neurological process that has its own autonomous dynamic’ (Kitwood, 1997a: 46).

**Present** – the situation in 2008 is difficult to gauge accurately at a national level, however with the Department of Health recommending that all those involved in the care of people with dementia should have ‘effective basic training, and continuous professional and vocational development in

dementia' (Dept of Health, 2008: 30), it is logical to assume that they view this matter as of primary concern. It is another matter whether or not sufficient resources will flow out from the Department of Health to back up any recommendations made for practice change in the sector, once the strategy is published in early 2009.

**Factor 6 (operational)** – the prevailing attitudes in the care process focused on the condition and not the person.

**Past** - The symptoms were being treated rather than the person, resulting in frustration, aggression and lack of real communication between professional care-worker and people with dementia. Loneliness and frustration could build up in the person with the resulting expression taking the form of aggressive or challenging behaviour. This invariably got interpreted as expression of the dementia syndrome, rather than as a need to communicate individual needs or wants. For Kitwood, this resulted in an observed 'ill-being' focused spiral for the individual (Kitwood, 1997a: 52). The description of this 'malignant' aspect in the social psychology of care was a breakthrough in terms of understanding the aetiology of a condition that hitherto had not been framed psychosocially, in what was later to be described as PCC.

**Present** – the situation has improved somewhat with a greater awareness in the care sector generally that individual needs have to be met more effectively and with a focus on the person rather than the condition. Evidence for this in the UK can be found in the current work of the Alzheimer's Society based in



London and its regional networks, in the current editions of the Journal of Dementia Care with articles on this subject (Allan, 2008, Wood-Mitchell and Milburn, 2008) and on the work of organisations such as Dementia Care Matters led by David Sheard (Sheard, 2008a, 2008b, 2009) and colleagues throughout Great Britain and Ireland. Department of Health initiatives including the National Service Framework for Older People and the new National Dementia Strategy, to quote two from a good many, are also contributing to a change of culture in care settings (Dept. of Health, 2001a, 2001b, 2007, 2008, 2009). There is still however a long way to go in this regard.

Factor 7 (**operational**) – Discovery of high-states of observed ‘ill-being’.

**Past** - High states of observed ‘ill-being’ were being recorded and noted down that used the evaluation methodology called Dementia Care Mapping (DCM) which evolved out of the work of Kitwood and Bredin (1992b). ‘Ill-being’ was associated with isolation, loneliness, lack of stimulation, lack of inter-personal communication and other important psychological factors.

**Present** – DCM (see below Section 5.3.2) has developed very significantly since its inception both nationally and internationally and is increasingly being used as an audit tool to measure the extent to which a ward or care-home environment is fully engaged in the use of PCC (Innes and Surr, 2001, Brooker et al. 1998). The tool, if properly used, can help a care-home, its staff and management contribute significantly to the reduction of individual states

of ‘ill-being’. This is to be welcomed, however more work needs to be done in this area.

An important implication of all the above points, and their respective complexity in combination, is that in reducing and eliminating the organisational, environmental, clinical and psycho-social climate that breeds and maintains MSP, there is a need for a systemically-based approach, investigating all of the factors referred to above and how each affects the other. Much needs to be done therefore, within residential and day care services, in ensuring that the values, beliefs, attitudes and learned behaviour of care staff and workers are geared towards fostering a care culture that has the person and their well-being at its heart. Kitwood and colleagues went on to describe and define this respect and dignity for the person within the concept of ‘Personhood’. It became defined clearly as follows: ‘a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust’ (Kitwood, 1997: 8).

Kitwood and Bredin propose a new person-centred paradigm within a psycho-social framework whereby people with dementia could be helped to live a life as full and rich as had previously been possible, in the ‘context of relationship and social being’ (op.cit p8), while taking into account sensory, emotional and psychological deficit. It means learning to live with the condition in a more positive way, focusing on individual ability, on personhood and what *can* be done rather than on the disability and what *can not* be done. I think here is a strong link back to the work of Rogers and his ideas on the importance of growth directed by the ‘client’. From a care-staff

perspective it means learning to work and carry out care practices in a very different way from what they have been accustomed to. This new approach which became known as Person-Centred Care (Kitwood and Bredin, 1992c) demands a great deal more of the care-staff in terms of working more relationally with people, more psychologically aware and more as members of a team committed to the provision of a much higher quality service.

Central to person-centred care is the concept of 'well-being'. Kitwood and Bredin looked at the evidence from bio-medical science and psychiatry and argued that: 'dementia care need not be a relatively passive attendance upon an elderly man or woman's psychological undoing. Rather, it may become an exemplary model of interpersonal life, an epitome of how to be human' (Kitwood and Bredin, 1992a: 286). It was in going far beyond the standard disease model and in proposing a New Culture of Dementia Care (Kitwood and Benson, 1995) that Kitwood and others made it theoretically, organisationally and operationally possible for the implementation of a new paradigm. From a bio-medical perspective and a standard disease model approach, dementia was an incurable neuro-degenerative disease where the focus was on the 'ill-being', the expression of disease pathology and what the person could not do. Medication could be used to treat the symptoms, but it would not be able to help understand or provide a framework that saw and valued the whole person in a psychosocial context.

This new psychosocial paradigm and what Kitwood also described as a 'dialectic' between 'neurological impairment, health and physical fitness, environmental,

biographical, personal and social psychological aspects' (Kitwood, 1997: 49) implied from a philosophical standpoint that dementia is both process and interplay between impairment and these other crucial factors in the life of the person living with dementia. There is therefore a focus on behaviour as meaningful and communicative, with 'personhood' and 'well-being' at its core. This means:

- 1) Creating and maintaining a new culture of person-centred care where the individual and their needs are valued over and above the needs of the routines or procedures in care settings.
- 2) Identifying, clarifying and developing ways to identify the presence or otherwise of person-centred care within the culture of the organisation. An evaluation methodology called Dementia Care Mapping (see below) evolved into a tool that can help identify a prevailing care culture, and provide aims and objectives for how to change it towards a more person-centred one.
- 3) Providing training in person-centred care approaches for care-staff across the sector.

### **5.3.2 Dementia Care Mapping**

Dementia Care Mapping (DCM) (Kitwood and Bredin, 1992b) is an evaluation methodology designed, as far as possible, to evaluate the impact of the quality of care from the perspective of the person with dementia receiving it. DCM becomes then a vehicle through which to build bridges of understanding between the person with dementia, their immediate environment, those around them and, in this study, the

impact on them of a session of DMP. DCM is governed by a manual that was DCM 7th Edition (Bradford Dementia Group, 1997) at the time the DCM data was gathered for this study. It has subsequently been updated to DCM 8th Edition. The roots of DCM lie in Kitwood and Bredin's own researches and studies in the dementia care field described earlier in this chapter. As a combined quantitative and qualitative evaluation methodology, it aims to measure across three dimensions: type of activity (Behaviour Category Code BCC), degree of comfort (Well/Ill being WIB), and time. BCCs are important because they identify the types of activity a person with dementia is engaging with. If these activities, during the course of an eight-hour map, are found to be small in number then as part of the person's care-plan an agreed objective can be to attempt to increase this range. Degree of comfort, as expressed by an individual WIB value, identifies the extent to which a person is in a state of Ill/Well Being expressed as a value or score from -5 to +5 respectively. These scores and their individual ranges can also be expressed as a group WIB value indicating, for example, the impact on the group as well as on the individual. An average WIB value could therefore be expressed as a WIB score for the whole period of observation (Brooker, 1995). In this study and described in Chapter 7, scores are expressed as both individual and group WIB values. The element of time in DCM is broken down and expressed in five-minute intervals or time-frames. Time-frames can therefore be used to identify the extent to which a person spends their time in an identified BCC, within a WIB value score, enabling meaning to be extrapolated carefully from the collection and analysis of scores and time-frames. DCM is increasingly being used both nationally and internationally as a way of auditing the quality of care in a residential care unit or hospital ward (Innes and Surr, 2001,

Brooker et al. 1998). DCM cannot identify specifically what people are thinking and/or feeling. However, given the problems of trying to understand the experience of people with dementia as far as possible from their own perspective, this is an important, impressive and validated tool in relation to quantifying the extent to which person-centred care practices are in evidence (Brooker D, 2005).

All mappers attend a recognised and accredited 'Basic User' training course that lasts three days, involving study, knowledge and practical experience about PCC and DCM, provided by the Bradford Dementia Group, University of Bradford or its affiliates. I attended this training in September 2001 and received my DCM (7th Edition) 'Basic User' Certificate, following completion of the course. This training provided me with the necessary knowledge and skills required to map effectively, although as with any skill, regular practice improves performance. The training in PCC and DCM I received in 2001 was influential therefore in my choice of this methodology for use in my own study, described in this thesis, with data collection taking place in 2002.

Prior to mapping, which usually involves two different mappers, sitting observing in different parts of a residential care home or ward lounge area, inter-rater reliability is tested as different mappers report and compare their recorded scores; this as a part of the on-going process determining validity. Validity of the different meanings mappers might ascribe to what they see, an important aspect of any kind of evaluation, is assisted by the use of 'Operational Rules' (Bradford Dementia Group, 1997). These are used to define clear parameters within which the mapping process

takes place and to ensure as far as possible that mappers can code their findings in the same way. Indicators of well-being would include assertiveness, bodily relaxation, sensitivity to the needs of others, humour, creative self-expression, showing pleasure, affection towards others and expression of a range of emotions (Brooker, 1995). Indicators of ill-being in contrast would show evidence of anxiety/depression, anger/aggression, agitation/restlessness, physical discomfort/pain and being excluded or feeling excluded from the group situation to name a few key aspects (Bradford Dementia Group 1997).

Other important aspects of DCM concern the importance of identifying where care practices may not be coming from a person-centred value base. These have been identified and described within DCM as ‘Personal Detractors’ or ‘PDs’ for short (Bradford Dementia Group, 1997). Where care practices are evidently having a significant impact of reducing ill-being and/or supporting/increasing well-being these are known as ‘Personal Enhancers’ or ‘PEs’ for short (Bradford Dementia Group, 1997). These ‘PD’ and ‘PE’ elements within DCM are increasingly significant, in the context of care-staff being able to recognise and value the contribution they are making to the quality of care, by having it witnessed and reported in the context of DCM. Within the context of DCM, evidence gained remains anonymous about who was involved in a ‘PD’ or a ‘PE’, from a care-staff perspective. This is meant to allay fears from the care-staff perspective that they are themselves under scrutiny, which could artificially change the nature and quality of their normal care practices and communications.

## **5.4 Contemporary developments and challenges in Person-Centred Care.**

The contemporary context, including challenges and developments within the field, are especially relevant to this study as the implications for future development of the use of embodied practices, for example, are bound-up with the current state of dementia care. Some of the challenges and barriers to the growth and implementation of PCC have already been presented above in the section on MSP (see section 5.3.1) and here the most significant are referred to in more detail. In spite of national developments in relation to the development of person-centred care approaches, including those most notably promoted by the Department of Health (2009, 2008, 2001a, 2001b), there is a substantial body of evidence identifying the poor quality of dementia care in the UK generally (Bowie and Mountain 1993, cited in Bruce et. al. 2002, Bruce et. al., 2002, Brooker, 2007, Sheard, 2008, Ward et. al. 2006b, 2005 2002a, 2002b). Difficulties range from people with dementia not being classified correctly as having dementia (Macdonald and Denning, 2002) to too much of a focus on physical care tasks and not enough on the psychosocial aspects (Ward et. al. 2005, 2006a, 2006b). Also as reported by Brooker (2007) there has been a degree of confusion and a lack of clarity surrounding differences in meaning between person-centred care, which has a value base in the work of Kitwood and Bredin (2002c), and that of individualised care as propounded by Standard 2 of the National Service Framework (Dept of Health 2001a). Brooker (2007) rightly argues that you can have person-centred care without individualised care, but you can't have individualised care without person-centred care; meaning you can't have a focus on the individual without taking into account their psycho-social environment, the culture of care and



all the other factors described above. Balancing this out somewhat, Baker and Edwards (2002 cited in Brooker, 2007) have developed a person-centred care element in the Department of Health's 'Essence of Care' document, aiming to benchmark standards in the field (Department of Health, 2001b).

Hill (2004), in her doctoral thesis, argues that the hegemonic values and organisational culture within the care-home make it very difficult for full implementation of PCC, even with the best of intentions. Also in a more contemporary paper she refers to the helpful concept of 'ideological hegemony' (Bauman, 2001 cited in Hill 2008: 22) that enables her to understand the course by which certain ideas and concepts come to prevail in a society or become hegemonic. For example:

...how a seemingly simple change in practice could be met with incredible resistance both passive and active, and to realise that if we continue to focus our efforts on practical issues of documentation, activities programmes and so on we will miss a very important battleground – where we are required to address the deeply entrenched individual and societal values which keep current practices firmly in place (op.cit.:22).

This reference to a 'battleground' is a powerful image to use and one that is echoed by the strength and passion of Sheard who I think would agree with Hill that it is 'deeply entrenched individual and societal values which keep current practices firmly in place'. Sheard I consider to be an important and contemporary player in the field of training and development within the provision of dementia care services. He worries

that change in contemporary practice is not happening fast enough across the sector to make much needed inroads to improving provision. He argues in this context that the implementation of Person-Centred Care is still seriously hampered by the current emphasis of care-staff 'doing to' people, as opposed to the more emotionally congruent and embodied experience of 'Being with' the person (Sheard, 2008a),

Being 'feeling based' starts with ourselves. Professor Tom Kitwood emphasised that it is a life philosophy – a set of fundamental beliefs about what it is to be a person. This emphasis is in danger of becoming lost. We need people who love or care for us to not just do things to us. We need a real connection, for people to have a sense of who we are, to feel how we are affected (Sheard, 2008a: 15).

Sheard goes on to describe his emphasis on, and use of, the term 'Being' (op.cit. 16) as a set of principles which he employs in relation to the development of his work and approach under the label of 'Dementia Care Matters'. He is also unequivocal in his argument that the quality of care provided to people with dementia across the care sector in the UK has to change much more rapidly than it has done to date, in line with person-centred care practices. He argues in his most recent paper that, 'the true quest for quality in a service begins with a staff team really seeing, hearing and feeling minute by minute the quality of interactions in people's lives' (Sheard, 2008b: 12). He challenges care-home managers and staff to make detailed observation really investigating the lived experience, rather than the assumed lived experience, of people in care. He refers to

...the subtle reactions, the missed moments, the repetitive nature of events, the stultifying boredom. A whole new picture is opened up to staff which can feel too brutal to face up to, too honest and too challenging. Measuring people's levels of boredom and its consequences strips a service back to its core (Sheard, 2008b: 12).

Sheard challenges contemporary care practices and practitioners to be more person-centred and more focused on the importance of feeling-based communications and feeling-based leadership, very much in line with similar research findings from Ward et al. (2004, 2005, 2006a, 2006b). Sheard has also developed an interesting observational tool which he says he has used a hundred times to categorise care settings which were 'brave enough to place themselves under this level of scrutiny' (Sheard, 2008b: 13), within one of six levels. His study indicated that only five percent of care homes achieved level one, which he described as 'exceptional person-centred care' (op.cit.:13), while seventy percent of homes, 'are below average to a crisis level' (op.cit.:13). It is difficult to find evidence to contradict Sheard's assessment and his arguments are consistent with the findings of others that the extent of PCC development nationally is full of difficulties (Bowie and Mountain 1993, cited in Bruce et. al. 2002, Bruce et. al., 2002, Brooker, 2007, Sheard, 2008, Ward et. al. 2002a, 2002b, 2005, 2006a, 2006b). Factored up to a national level, this would indicate serious challenges and problems in the provision of high-quality dementia care, that even a brilliantly effective National Dementia Strategy for 2009 would be hard put to change.

The latest evidence from the listening exercises carried out by the Department of Health in 2008, towards the creation of a National Dementia Strategy, conclude that:

...(s)ervice redesign and innovation will be needed to achieve the transformational change required to ensure that all those with dementia have a chance of receiving high-quality diagnosis and care, rather than just a minority receiving it. Such change will not be simple, but it is what the people who use the services want, and what the evidence base indicates will be most effective (Dept. of Health, 2008: 23).

Another important reason why PCC may have failed to root and develop effectively in the care sector over the past twenty years is because Kitwood placed too great an emphasis on examining care cultures, their impact on people living with dementia through DCM, without enough of a focus on the care-staff delivering the care at an operational level, resulting again in a two-tier system (Sheard, personal correspondence). One tier involves care-staff using PCC and being treated in person-centred ways, the other involves care-staff not receiving person-centred care themselves but being expected nevertheless to practise it without person-centred leadership, management structures or support for it in evidence in the organisation.

Both person-centred care and the use and development of DCM are pioneering developments in the range and quality of dementia care now being provided with each, supportive of and necessary to, the other: 'Although some of his writing and ideas may have been difficult to grasp by those providing direct care, the creation of Dementia Care Mapping (DCM) provided a means of very concrete feedback on the

quality of person-centred care in this respect' (Brooker, 2004: 219). A problem has been created in what I describe as the shadow-side of PCC, and DCM in particular, resulting in care-staff becoming suspicious of a methodology that involves their practices being witnessed, and to a certain degree assessed. In spite of an overt quest to better understand the lived experience of the person with dementia in care, it is reported that care-staff are nevertheless anxious of DCM and the obtrusive nature of observing care practice (Brooker et al., 1998). From the perspective of the care-staff (and taking an inter-subjective perspective) this is perhaps a perfectly natural reaction to being asked, or expected, to practise in these 'new'(sic) and challenging ways without any forthcoming increase in rates of pay, training or education to acknowledge and address the increasing levels of skill and ability required.

An important question for me, also in a contemporary context, concerns the chances for embodied practices to be better recognised and used, running parallel to the development of truly person-centred care cultures in organisations. It is an important part of my argument for inclusion of a detailed chapter on PCC in this thesis, that embodied practices can naturally find themselves a home within the context of care settings properly implementing and developing PCC. I am currently running a Dance Movement Psychotherapy Service for an NHS Trust in South West Yorkshire that is developing service provision in that area. Locally it is a significant development but not one that is likely to influence the development of DMP practices nationally.

Quite naturally there have been developments and challenges to the growth of PCC and DCM since the death of Professor Kitwood in November 1998. These challenges,

for example, also include the lack of awareness in Kitwood and Bredin's writings of the importance of dementia care taking place with awareness of race, gender and citizenship; the lack of an awareness of the importance of embodiment and embodied practices; lack of awareness of the importance of dementia care taking place within a relational context (Adams, 2005). It has also been proposed, for example, that person-centred care evolves into a more systemically rooted framework described as 'Relationship-centred Care' (Nolan et. al, 2002), which I consider a welcome development. Some of these challenges have been addressed by the Bradford Dementia Group and by Professor Brooker in particular, who has responsibility for its development and who has reviewed, collated and attempted to bring together all Kitwood and Bredin's ideas expressed in their respective papers and books on PCC under one heading. This work takes the form of an acronym referred to as the 'VIPS' framework (Brooker, 2007) where PCC is presented in four different themes. 'V' stands for valuing people, both those living with dementia and those caring for them, while at the same time promoting, 'citizenship rights and entitlements regardless of age or cognitive impairment, and rooting out discriminatory practice' (Brooker, 2007: 27). The letter 'I' means treating people as individuals while, 'appreciating that all people have a unique history and personality, physical and mental health, and social and economic resources, and that these will affect their response to dementia' (Brooker, 2007: 44). The third letter, 'P', means being able to see the person's world from their perspective, 'recognising that each person's experience has its own psychological validity, that people with dementia act from this perspective, and that empathy with this perspective has its own therapeutic potential' (Brooker, 2007: 63). The fourth letter 'S' relates to the theme of the importance of the social environment

in the provision of psychological needs, ‘providing a supportive social environment recognising that all human life is grounded in relationships and that people with dementia need an enriched social environment which both compensates for their impairment and fosters opportunities for personal growth’ (Brooker, 2007: 82). It is significant that the ‘VIPS’ framework can be seen to encapsulate missing aspects including those identified by Adams (2005) referred to above; the importance of ‘citizenship and entitlement rights’. The importance of growth in a contemporary dementia care context is also acknowledged in the ‘VIPS’ framework, which I think maintains that link back to Kitwood and Rogers before him, as discussed in section 5.2.2 above. The ‘VIPS Framework Tool’ (Brooker, 2007: 119) has also been developed on the back of the ‘VIPS’ work as a way of identifying and assessing the extent to which an organisation, its management ethos, its structures and care practices all systemically contribute to the creation of PCC. This is a welcome development and fills a gap that DCM has not been able to fill, namely the assessment of complex organisational processes and structures, helping elucidate why and how care organisations, at times succeed in creating and sustaining well-being while at other times they fail in this task (Sheard, personal correspondence).

Brooker and Woolley (2006) have researched the development of what they have described as an, ‘Enriched Opportunities Programme’ (Brooker and Woolley, 2006). This involved collaboration between the Bradford Dementia Group and the Extra-Care Charitable Trust, a private provider in the UK of residential care-homes and packages of care for older people and people living with dementia. The aim was to develop and research the development of the ‘Enriched Opportunities Programme’

from a 'theoretical ideal into a workable practical model within extra care housing and nursing home care' (Brooker and Woolley, 2006: 6). The research and development work involved the putting together of a forty strong 'Expert Working Group' (Brooker and Woolley, 2006: 28) of dementia care specialists from all fields to advise in the development of this research based project based in four different sites in the Midlands. I was a member of this 'Expert Working Group' in my capacity as a Dance and Movement Psychotherapist. I was able to mentor a member of staff in one of these sites in their newly identified and pioneering role of 'Locksmith'. Results of the research project indicated an improvement in care-staff practices, statistically relevant increases in observed 'well-being' (DCM 7<sup>th</sup> Edition) maintained on follow-up and 'overall average higher levels of well-being regardless of cognitive impairment or level of dependency' (Brooker and Woolley, 2006: 10). There was also a reduction in overall levels of depression as identified by the Cornell Scale for Depression in Dementia (Alexopoulos et al. 1988 cited in Brooker and Woolley, 2006: 10) representing significant achievements.

Much of what I have discussed in this section relates to the challenges and barriers to the development of PCC in the UK and internationally. However DCM is currently being used as a very valuable tool in assessing the quality and impact of care-practices, including environmental, psychological and other effects on the person with dementia and this must not be denied. PCC is increasingly acknowledged to be a very effective method for changing things for the better; however there is still a long way to go and this section has attempted to elucidate some of the most important barriers to its development.



## 5.5 Concluding thoughts

I have discussed in some detail in this chapter the importance of person-centred care for people living with dementia and in enabling care-staff themselves to be better managed and led in more person-centred ways. I have discussed its roots and origins, opportunities for practice change, and the challenges and barriers to its future development. PCC and its on-going development is a context in which DMP takes place, and it is vitally important therefore, that PCC is understood as both a valid framework for improving care practices and a psychologically oriented platform or springboard for developing DMP. For the care-staff working on the ground, delivering PCC is not just about ‘doing’ better care, it is about having a more rewarding experience; one that deepens, widens and extends the scope, range and humanity of care practice at national and international levels. This is also an aspiration that is close to my own heart as a researcher/practitioner, and I argue in this thesis that DMP can fill an important gap in the context of deepening, widening and extending scope, range and humanity by improved awareness of and training in ‘embodied practices’ in PCC. While there is an important synergy between DMP and PCC, the need is definitely there for better access to DMP, supporting a quality of life giving hope and affirmation that life can be well lived, in embodied ways, in spite of a dementing condition; with care provided in a consistent way by the best skilled and experienced care-staff along the way. This is nothing less than all people living with dementia and those who care for them *deserve*, in the context of access to the best-researched assessments, diagnostics and treatments available.

## **Chapter 6 Fieldwork**

### **6.1 Introduction**

This chapter presents the detailed aims of the fieldwork phase and how these were investigated, within the context of a staff training and development programme, specially designed for the participating Mental Health NHS Trust. The fieldwork took place on a dementia care ward where the data was gathered, including the Dementia Care Mapping (DCM), Video Tape Recording (VTR) and care-staff questionnaires. The ward was staffed by the usual complement of Ward Manager, Nurses, Health Care Support Workers and auxiliary staff with access to medical support and other Allied Health Professionals. Ten staff from the ward were involved with six sessions planned, each to be DCM mapped. In practice only five mapped sessions were possible; three of them were facilitated by me, the others by the care-staff themselves. The third and last session I facilitated was mapped, videoed and analysed here.

### **6.2 Aims of the fieldwork phase**

The aims of the fieldwork phase were to identify the effects of a programme of Dance Movement Psychotherapy on people with dementia and their care staff in a hospital ward in order to develop a better understanding of the processes taking place. There were three main aims:

**Aim 1:** to observe the effects on observed well/ill-being of people with dementia participating in a DMP session

**Aim 2:** to identify the embodied practices occurring during the session and their impact on both people with dementia and their care-staff

**Aim 3:** to identify the impact of the DMP session on the care-staff

The data gathered was analysed in relation to: the impact on observed well/ill-being in people with late stage dementia; the importance of non-verbal embodied practices in improving communications between people with dementia and their care staff; the importance of staff attitudes, confidence and capacity (increases or otherwise) in providing psychosocial activities. Conclusions drawn aimed to further knowledge and understanding about the effects of DMP, with particular relevance to using embodied practices, in improving communications and person-centred care. Methodologically, the fieldwork was carried out within the paradigm of RC as ‘practitioner-researcher’. Theoretically, the research is located within the anthropological concept of ‘participant observation’, as first described by Malinowski (see Chapter 2, 2.3). This means the researcher-practitioner is immersed in the fieldwork in such a way that, described in a more contemporary sense, ‘...objectivity can be approached through a heightened sensitivity to the problem of subjectivity, and the need for justification of one’s claims’ (Robson: 1993: 195). The fieldwork phase has also attempted to do good science by paying close attention to reliability, to validity and the creation of rich data by way of making and then analysing the close connections between the different, also embodied sources of data; these include DCM, the VTR transcript, the questionnaires, coupled with my own analysis of meaning created in response.

### **6.3 Outline plan of the fieldwork phase**

The following sections detail the research areas under investigation and referred to above. They deal first ( see section 6.3.1) with the impact of DMP on the group as identified by Dementia Care Mapping (DCM) as previously presented and discussed in Chapter 5. The use of VTR is referred to in this section as an important part of the study into the effects on the group, the individuals and participating care staff. VTR also raises some ethical issues and these are presented here. The next section (see 6.3.2) identifies embodied practices as they impact on the person with dementia taking part in the session including the care staff. VTR was also used in this subtle and challenging attempt to capture the complexities of human movement and non-verbal communications. Section 6.3.3 investigates the impact of the work and approach on the participating care staff and involves the use of evaluation questionnaires with a range of different types of question, including the use of Likert Scales.

#### **6.3.1 Aim 1: To observe the effects on well/ill-being of people with dementia participating in a DMP session**

The effects of the session on people with dementia were identified in part using DCM carried out by a trained DCM mapper, using the 7th edition of the DCM manual (Bradford Dementia Group, 1997). DCM as an evaluation methodology is constantly evolving in response to its application and use in the field of dementia care, the process overseen by the Bradford Dementia Group. The type of edition used reflects, to a trained and experienced reader, the degree of evolution of DCM. The 7<sup>th</sup> edition

was the latest version in 2001 when this data was collected. The trained mapper made pre- (30min), during (1hr) and post- (30min) intervention scores for each of the five sessions that took place on the ward, making a total of 10 hours of DCM. Six sessions had been planned but staffing problems meant the sixth session could not be mapped. Each weekly session lasted approximately forty-five minutes to an hour. Usually six residents and three staff attended on a regular basis. The mapper carried out detailed observations at five-minute intervals in order to evaluate individual states of observed well or ill-being for all patients taking part. The values were combined to gain a group score or group results for each of the sessions. The rationale for the mapper making pre, during and post measures was so that the intervention itself could be more clearly defined in relation to what preceded and followed it. The data produced should therefore consist of a more accurate reflection of its impact on the person within the context of their experience on the ward and their state of observed well/ill-being, before, during and after a session. Data produced by the mapper was not given to me until after the fieldwork phase was complete, in order that it not alter or influence the content of the sessions, or the nature of the relationships established. The creative/ expressive content of the mapped sessions was new to the mapper, who was not involved in the training programme or the pre and post session preparation and review.

VTR was used to capture the effects of the work on film in order to enable technology to increase the flexibility and ease of information access. Palo-Bengtsson (1998) employed VTR data in her influential study in Sweden that involved the use of a stationary camera in the corner of the room. 'It was possible to review events as

often as necessary in a variety of ways for example in slow motion, frame by frame, forward and backward' (Palo-Bengtsson, 1998: 19). In this study an independent film-maker was employed and they used one hand-held camera to capture more data than would otherwise have been possible using a stationary device. This was also a method favoured by Bright (1988), the pioneer of music therapy in dementia care. One session only was filmed on the ward on the morning of 17<sup>th</sup> April 2002 ( session no. 3) providing the VTR data that was subsequently transcribed and analysed.

The use of the VTR as a research tool was important in providing 'an accurate, complete record' and in minimising 'the selective bias and memory limitations' (Palo-Bengtsson, 2000b: 27). This meant that it would be easier to review the content of the session as it could be played and reviewed time and again without being dependent on the limitations of the researcher's memory. Another important factor was that obtaining information useful in research terms was notoriously difficult with people who have moderate to severe dementia. This was partly because of their difficulties in reporting back their experiences, especially when, according to Morse, interesting moments in a session happen so quickly with rapidly changing characteristics (Morse 1991, cited in Palo-Bengtsson 2000: 17). The VTR method for data capture, set alongside the DCM scores, combined with my own experience as practitioner / researcher, increased the reliability of the information obtained and presented more opportunities for later in-depth analysis. The VTR was also important because it enabled me to 'build bridges of understanding' between what I had seen, noticed and remembered of the session and what I had not; for example, the subtle, embodied and non-verbal cues between patient/staff and between patient/patient.

The use of VTR in dementia research does present important ethical issues as people with dementia are more exposed. However according to a relatively recent research overview of the use of VTR in the field, people living with the condition are increasingly becoming involved in research and directly influencing planning, policy and practice as a result (Knight, 2005). These are, I would argue, important and welcome developments in the field. It is necessary, while using VTR, to uphold for every person their: 'dignity, rights, safety and well-being' (Knight, 2005: 32). Interestingly, Knight also cited a Department of Health paper which argued that, 'a deciding ethical factor in involving people with dementia in research is whether the research question can only be answered if those participating consist of people with dementia rather than those who do not have a cognitive impairment' (Dept. of Health 2001a, cited in Knight, 2005: 32). I agree with this position and that the questions posed in this study relate especially to those with cognitive impairment where embodied practices could not be best understood without the use of VTR data capture. Also according to Knight (2005), VTR captures moments that would be missed by other methods. Alongside these considerations there was the on-going necessity, to be aware within a person-centred care perspective, of any distress caused to any of the participants; in which case the filming would be stopped. All these considerations were upheld in relation to the use of VTR data capture in this study and other ethical issues are referred to in Section 6.9 in this chapter.

Choices have also been made about the content, context and direction of the analysis (Sandelowski 1994, cited in Palo-Bengtsson, 1998: 19). These choices were made

after repeatedly watching the VTR, writing and re-writing the transcript, checking for accuracy and staying as close to the film content and context as possible. The transcript and the DCM data needed to be tied together in a way that enabled comparison and analysis of the two data sets and this was done by making the first column in the transcript relate to 'Time', thus linking it with the DCM data. The process was very time consuming. However, the rewards have been rich and surprising: I have been able to identify and differentiate thirty-three themes and their frequency of occurrence in the hour-long session (see Appendix B 'Differentiating the VTR Transcript Themes and Frequency of Occurrence').

An area of potential bias concerned the impact of observers on the outcome of sessions; staff for example although in the process of being trained, were known to patients and vice versa, therefore it was unlikely that they would be disturbed by them. However, new faces can have a powerful effect, especially in session one as there was much to be done in terms of creating a safe space, an atmosphere of trust and a place where participants felt able to express themselves freely. The presence of the film-maker and Trust Mapper can be ameliorated by them visiting at least once before the start of the study in order that they become known to patients. Fortunately the Mapper, as Deputy Unit Manager was known to patients; however the film-maker was unable to make a preliminary visit. By using a small hand-held camera rather than something larger requiring a tripod, she reduced the potential negative impact of obtrusive equipment.



**6.3.2 Aim 2: to identify the embodied practices occurring during the session and their impact on both people with dementia and their care-staff**

There are no validated scales or tools that can fully investigate the nature of embodied practices. This is because embodied practices are complex, subtle and encompass many different elements in intra and inter-personal relations. These include patterns of movement, gesture, posture and non-verbal body-based communications occurring in real time, with and between people. Dance Movement Psychotherapists frequently employ a methodology called Laban Movement Analysis (LMA), developed by Rudolph Laban out of his original time and motion studies of pre-second world war factory workers in Germany in the 1930s (Laban, 1967, see Chapter 4 section 4.2.2). LMA as previously discussed seeks to identify and analyse human movement patterns within a methodology that understands movement happening in a number of planes, in relation to personal movement dynamics (bound/flow) and in relation to force and direction. LMA has proved to be a valuable and essential tool for Dance Movement Psychotherapists, in being able to analyse movement patterns and behaviour as an important part of clinical practice.

Analysis of the VTR data within a phenomenological perspective would enable the recognition of non-verbal embodied behaviours including movement patterns, themes, gestures, postures that contribute to supporting, encouraging and improving communication and relationship. These were identified and logged through a process of repeated viewing and re-viewing of the VTR, and the video film was gradually

converted/transformed into a written manuscript (Appendix A). The video film and the written manuscript together were examined and themes identified. The themes were then analysed in two different ways; first in relation to being able to identify embodied practices from the patient and care staff perspective, second in relation to aspects of the session that could be generalised in the form of over-arching 'Meta-Themes' (see section 7.6.8).

The importance of the study, in this non-verbal embodied area of dementia care practice, is founded on the premise that it is the embodied state of people with dementia and how they express themselves through their bodies that we as care-staff and psychotherapist need to pay much more attention to. This so far neglected area of research, study and practice could reveal more about the unique personal resources and capacities still available to people that have remained an as yet untapped area of potential in dementia care work generally. This view is supported by other researchers in contributing to a better understanding of the importance of non-verbal, embodied and emotional communications in care work with people with dementia (Haak, 2006, Phinney and Chesla, 2003, Kontos, 2005, Ward, 2005, 2006a, 2006b).

Care staff session preparation and review periods, facilitated by me (RC), took place thirty minutes before and thirty minutes after each of the sessions. These periods were important as an aspect of good practice, in order to identify how patients were feeling before a session began and to assess whether or not it was possible for them to attend. Care-staff contributed to identifying whether or not a patient's mood or behaviour made it potentially unsafe for them to attend for whatever reason. As researcher/practitioner, I took a final decision in consultation with staff. Review

periods also made it possible to jointly assess the impact of the session on those taking part identifying any potential themes or activities that had emerged. These could be used at the next session in order to further the impact and development of the work on those taking part.

### **6.3.3 Aim 3: to identify the impact of the DMP session on the care-staff**

Investigating whether or not the training programme had increased the confidence and capacity of the care staff to better meet the needs of those within their care was an essential aim in the provision of the staff training and development programme and essential in this study. The programme took place between March and May 2002 and began with a training day in Person-Centred Care, followed by three days off-site arts-based training making a total of four training days (see below) and three days on-site, session-based training. A month after the training programme a Review Day was held where staff were asked to make a presentation, detailing the impact of the programme on them and on selected people with dementia, to an invited audience including members of the NHS Trust Board.

## **6.4 Training and development programme.**

The details of the training and development programme were as follows:

### **Training Day 1**

A day's training in 'Person-Centred Care' was delivered by a specialist trainer in Person-Centred Care and Dementia Care Mapping, registered with and trained by the Bradford Dementia Group at the University of Bradford.

### **Training Day 2**

An introduction to arts and dementia work, music, movement dance and song skills.

Delivered by RC.

### **Training Day 3**

Reminiscence and music, movement, dance and song skills.

Delivered by RC.

### **Training Day 4**

Groupwork and Leadership Skills, music, movement, dance and song skills.

Delivered by RC.

### **Review Day**

The day reviewed, presented and celebrated achievements, bringing the work to the attention of a wider group of staff both within and outside of the Trust. It enabled the transfer of learning and supported the work to continue on a sustainable basis.

Several questionnaires were used as part of the evaluation process investigating confidence and capacity and the impact on the care staff. An 'On-going Evaluation Questionnaire' (OEQ) (see appendix D) was presented after the first training day had taken place together with the session following it. After completion of the first session on the ward a 'Participants Evaluation Questionnaire' (PEQ) (see appendix E), was used. Questions were asked relating to evaluation of the first session OEQ, effects on patients and relevance to National Vocational Qualifications (NVQ). A question was also asked relating to the goals of participating staff. The PEQ considered the relevance of the syllabus including: 'Music, Movement and Song',

‘Reminiscence and Resources’ and ‘Groupwork and Leadership skills’ and whether staff found the syllabus ‘very helpful’ through to ‘confusing’ on a five-point Likert Scale. Questions were also asked relating to the key professional and personal benefits of those attending: whether or not staff thought that the knowledge and skills gained had increased their confidence in their work? Also on whether or not any skills gained improved the quality of care service provision, increasing the confidence and capacity of the staff team to better meet the needs of those within their care more imaginatively and more effectively? The questionnaire further identified any anticipated difficulties in implementing the ideas and techniques in the care setting.

## **6.5 Building Bridges of Understanding through training and the transfer of learning**

The programme combined off-site training and on-site practice opportunities that incorporated a range of approaches to training. These added up to a complete strategy for the identification of training needs; the design of an innovative programme to meet those needs; the implementation and effective evaluation stages built in; coupled with opportunities to identify, present and be given feedback on achievements (Review Day) by colleagues and senior managers in the NHS Trust.

This training programme design was founded on the premise that off-site training needed to be grounded in the workplace with supervised experiential on-site practice that enabled learning and development to be tested and grounded. This approach to training had evolved in part didactically out of my experience with Living Arts Scotland Ltd, of which I was a co-founder and Training and Development Manager

between 1992 and 2000. Prior to that, between 1981 and 1984 I had been Head of Communications through Drama, Group Tutor and Course Director at the Brathay Hall Trust in Cumbria. It was then, and still is, an important provider of leadership and management development training and this experience too was formative in my understanding of training and development matters. It was also during my time at Brathay that I gained a Diploma in Training Management with the Institute for Training and Development in Marlow building academically on this previous training and development experience.

Importantly, I had learnt academically and experientially that setting out to train anyone in a new skill presented problems, especially when there had to be a transfer of learning from an off-site setting to the work environment where the newly learnt skills needed to be applied. According to Greenaway who is a leading researcher in the transfer of learning, 'the greater the difference between the two situations (training and work), the more the learner must do to bridge the gap' (Greenaway, 2005: 1). I was able to help support the learner bridge the gap described here in several ways. First, the off-site training days were supported by on-site sessions, facilitated initially by me followed by a gradual handing over of this responsibility to trained care staff; this process involved on the job demonstrations, support, feedback and mentoring for staff including pre and post session preparation. I had attempted to help bridge the gap for staff by facilitating sessions with them in role as participant/observers. Secondly, the initial training day in person-centred care had aimed to be a 'bridge of understanding' (again bridging the gap) between the everyday practice of care about which they were familiar and the new creative and

therapeutic ways presented in the other days about which they were unfamiliar. This initial training day helped raise care-staff aspirations and expectations about what had happened and what was to follow. It could be argued that if I was expecting care staff to make small realistic adjustments or changes to their practice, then they would not need much follow-up as the 'gap' was not too large for them to negotiate. The training had been planned around and involved a whole new way of thinking about their work necessitating the application of skills and knowledge that needed to be implemented in creative, flexible and experiential ways. As such this required that follow-up and the transfer of learning be well supported. As Greenaway argues, in another paper; 'the best programmes are a magical mixture of contrasts – in which a careful overall design links together the more creative and adventurous aspects of a programme' (Greenaway, 2002: 8). This indeed was my intention in relation to the training programme; that it should be a multi-sensory, embodied and creative experience, with a sense of adventure, fun and trust; coupled with tolerance of ambiguity, including most importantly that of 'difference' and 'otherness' on the part of the care staff towards the people for whom they cared. Overall the training programme aimed to make improvements to the service and delivery of care on the ward within a more person-centred care environment.

## **6.6 Principles and Practice**

The programme was carried out with the following at its core:

- There was a person-centered approach respecting at all times personal dignity, freedom of choice and the needs of all those taking part however expressed.

- There was encouragement of communication and relationships between staff, staff and people with dementia and between people with dementia and volunteers including trainee nurses, that valued the expression of life experiences and stories however and whenever they were expressed; whether verbal and/or non-verbal, whether through movement, dance, song, music, story, reminiscence or poetry.
- There was support for care staff to value their own unique skills and life experiences that formed the basis of their enhanced ability to improve relationships with those in their care and in turn, their ability to run high quality activity programmes in the long term.

These principles were clearly stated in the proposal that was presented to the Trust. There was an assumption on my part that staff would be able to enhance their ability to improve relationships with those in their care, by first valuing their own skills and life experience. This assumption was based on evidence provided by analysis of completed staff evaluation questionnaires following previous experience of running training and development programmes in Scotland. This assumption was tested as part of this study. The programme valued the following for the person with dementia as contributing to enhanced observable well-being:

- 1) Improved awareness of other people.
- 2) Improved awareness of surroundings.
- 3) Improved self-esteem.
- 4) Increased expression of feelings.
- 5) Provided opportunities for reminiscence and sharing life experiences.



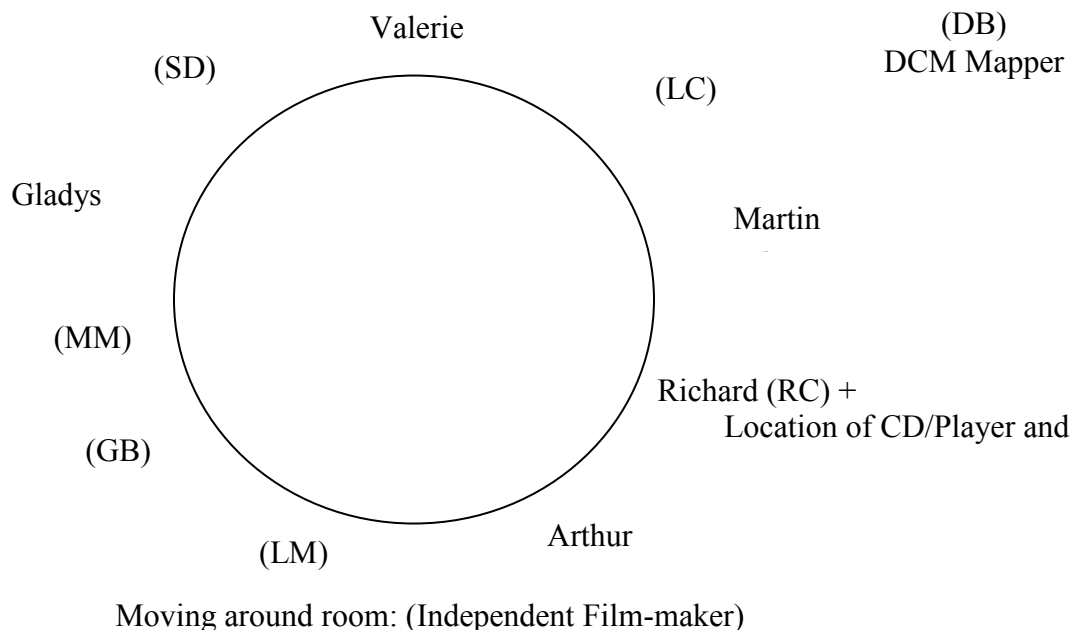
- 6) Enhanced physical mobility.
- 7) Reduced behaviour described by staff as difficult or challenging.

My personal log of participating staff responses also formed part of the data analysis and was used to identify issues relating to the development of staff confidence and capacity regarding the provision of this approach.

### 6.7 Setting up the filmed session

There were four patients and five staff (Diagram 1) sitting in a circle in armless, upright chairs.

**Diagram 1: Group seating arrangements**



The intention was to try and ensure the staff were sat between patients and not next to each other if this could be avoided. A normal session would involve a ratio of two

staff to between six and eight patients depending on levels of frailty and confusion. For example, the more confused and frail the patient, the greater the need for a small group. Participating staff were high on this occasion and untypical of a normal session as this was part of a training programme and required all staff to be given a session place. Determining group numbers is not an exact science, but it is best decided on a session by session basis and usually done in the pre-session preparation that takes place thirty minutes before the start, taking into account patient mood, sensitivities to others and suitability on the day.

Room and equipment preparation involved moving armchairs out of the way and placing comfortable armless chairs in a circle in the middle of the room. Scarves were placed on the chairs to be occupied by staff so that they would know where to sit. Props including musical instruments, scarves, ribbons on sticks and elastic were laid out immediately behind where I was sitting (see Diagram 1), facilitating ease of access to music, player and props. DCM mapping carried out by DB began at 9.40am in the main lounge. At around 10am I gathered the five participating staff in the room I had prepared, in order to have 'Pre-session Preparation' planning and to familiarise myself with how patients and staff were feeling that morning and if there were any contra-indications to attendance. For example, Bill and Brenda were unable to attend (Bill had attended twice before; Brenda once). This meant the group would unavoidably be two patients short. These sorts of changes were to be expected given the levels of frailty and confusion present. Patients and staff began entering the room at 10.25 am, which signalled the end of the pre-session mapping period and the beginning of the mapping period for the session itself (see Appendix C).

## **6.8 The session itself**

A session has three principal elements. An opening or warm-up followed by a development on a chosen theme or subject, leading to a wind-down or closure. As patients and staff entered the room they were escorted by staff to their armless chairs. During this I played taped music from the 1940s that was familiar and easy to listen to. I welcomed patients individually giving hand and eye contact. Patients in wheelchairs are also accommodated whenever possible. The warm-up usually involved a focus on body awareness begun with the hands and feet that used verbal prompting and included stretching, shaking, tapping and twisting different body parts. The intention was to enable a connection with the breath and the process of breathing to deepen awareness of the vital connections between breath and movement. On this occasion, the group held hands and swayed rhythmically and in unison with the music. This stimulated energy within the group. Movements used were relevant and familiar and ones that would have been used in everyday life rather than part of any standardised exercise programme. For example, the group may simulate the washing of hands. I was also at this time able to identify individual movement patterns within the group and encouraged patients and staff to see and follow the movements of others and sing along if they chose to. This encouraged the stimulation of observational and kinaesthetic skills by inviting patients to copy the movements of others (this process is described in more detail in Coaten and Warren, 2008). The purpose of this warm-up part of the session was to enable patients to feel at ease and comfortable in the situation and with each other including staff. The circle format was also significant in contributing to an atmosphere of safety (Meekums, 2002), and

familiarity and acceptance supporting a lessening of fear and anxiety, or the excess disability (Schwab et al., 1985). It was also important to help support and maintain physical condition and mobility through gentle movement to music that was enjoyable, accessible and with a sociable aspect as well. This stimulated a sense of well-being and also helped individuals warm-up psychologically (Coaten 2001, Crichton 1997, Perrin 1998).

This was followed by contact extended to include other parts of the body exploring the potential for movement within the group that stimulated sensory and proprioceptive input. This extended to foot tapping and hand clapping and patients were invited verbally by me to use their hands in a tapping motion up and down their arms. A variety of props were used exploring fully their potential for sensory stimulation. This for example included a long circular pink elasticated band (three metres long), that was used to join everyone together in the circle. Patients were invited to hold onto it and move it gently to the music however they wanted, using either one or both hands or neither. I decided to use the elasticated band to establish contact between individuals; it enabled patient participation, brought the group together and increased the potential for them to explore their movement range. This movement-based exercise was accessible to patients and encouraged the experience of everyone moving rhythmically together and in unison as a group; this supported increased mobility and stimulated energy within the group. It is also a technique used on a regular basis by Dance Movement Psychotherapists with a variety of groups and settings.

Skill, empathy and well developed communication skills are needed by the therapist in order to make genuine contact without being patronising or condescending. The goal is at all stages of the session to be able to acknowledge and where possible celebrate remaining potentials, as expressed both verbally and non-verbally, through movement and dance; emphasising the unique qualities of the individual and to reach the core of the person inside the confusion, conveying love, respect and understanding (Kitwood, 1997a). Crucial to making contact were the ways through which this happened. Focus was on restoring a sense of person-hood and self-esteem. During this part of the session (10.45am) I noticed Gladys had just begun to leave her seat, possibly restless or needing to start walking; I could not be sure which. In response to this movement behaviour, I was able to reach under the elastic and move towards her across the centre of the circle. I held out both my hands towards her, she took them and we rocked side to side in time with the music; we also made strong eye contact with each other which was important in helping her to know that she was both witnessed and validated non-verbally through the action. Eye-contact has been considered by some as communicating the most truthful messages in human communication (Ekman and Friesan 1975, cited in Zachow, 1984: 20). Observational and kinaesthetic skills were also stimulated. Having invited Gladys to move with me, I was aware through the hand contact how she initiated the movements we shared together and I was able to mirror them. I was also able to sense and follow the movements in her arms and hands, mirroring them in the process. Mirroring is an important technique used by DMPs that was first understood and described by Marian Chace, one of its leading pioneers in the United States (Chace, 1975). It is also common practice throughout a DMP session that the psychotherapist looks for the

different ways people initiate their own expressive movement sequences, often revealed creatively and improvisationally during the session (Goodill, 2005).

Emerging themes and/or movement ideas were identified and explored during the development part of the session that followed the warm-up, especially those which have potential for development. 'This may involve sharing songs, stories and occupational movement skills that have been retained and/or stimulated in response to the movement' (Coaten, 2002a: 389). Activities were designed to be multi-sensory, to engage the creative imagination and to offer opportunities for self expression according to individual need. During the development part of the session, instruments were passed around and used, music was also played at the same time and patients used drums, maraccas, shakers and tambourines in different ways. Taped music was also turned off at times to allow the group to hear more clearly the sounds they were making on their instruments. After this, scottish reels were played, patients held hands and moved rhythmically and in unison; some tapped their feet on the floor. Singing also took place during the development phase and the ribbons on sticks were used before making a display of them on the floor in the centre of the circle. At this point I had re-assembled the ribbons on sticks on the floor, the intention being to ask patients to re-identify with them, together with any further associations in the shapes and colours. Memory recall was vital to the process and was stimulated through the use of a variety of stimuli: sensory, visual, auditory and kinaesthetic. In this instance memory recall was stimulated by patients being asked to comment on what they saw laid out in front of them on the floor. The importance of memory recall may be a contributing factor in giving back to the person a sense of self-identity (Woods,

1998). A consequence of being given back a sense of identity or being supported in making sense of the fragments of memory, of language and understanding, may see a reduction of aggressive and challenging behaviours where the goal is to improve the patient's quality of life (Cohen-Mansfield, 2000).

Up to this point fifty-five minutes had passed before the wind-down and closure. The closure of the session took approximately ten minutes and involved the singing of hymns for part of the time. This had been initiated by a member of the group. Songs and music hold associated memories and these are released by sensory triggers (McMorland, 1998). Patients were invited for any further thoughts, comments, ideas, feelings, memories, songs and/or associations with what had taken place. Short term memory can be very poor, making it difficult for patients to remember what had just taken place, however the intention to support this approach by the DMP is an important part of the therapeutic and evaluative part of the session. I was able during this time to summarise the contents of the session and reflect upon them verbally and non-verbally with the group. Participants were thanked for their participation and the session closed with patients being helped by staff to leave the room. Again music was played to accompany departure. I then carried out a post-session review with the participating care-staff remembering the ways in which patients participated or not and how session content had drawn on any of the following: important personal life skills; local knowledge and history; folklore; occupational skills as well as the cultural and life context through which people had lived. Key moments in the session that care staff considered important were also discussed; as was future participation of patients and ideas related to further and on-going development of the approach.

## **6.9 Ethical considerations**

The ethical considerations of working with people with dementia are fraught with difficulty on the basis that they are often unable to give ‘informed consent’ which is at the heart of all ethically based research (Dept of Health, 2001c). This implies that their potentially limited powers of cognition expose them to being unable to comprehend what is being asked of them and thus potentially resulting in infringement of their dignity, their rights, safety and well-being. Indeed as established by the Dept. of Health Governance Framework, ‘the dignity, rights, safety and well-being of participants must be the primary consideration in any research study’ (Dept. of Health, 2001c: 8). All involved in treatment and research, especially vulnerable adults for whom ‘informed consent’ is not possible need at all times to be protected. Any good contemporary assessment of the ability of the patient to ‘consent’ to treatment has to take into account, an assessment of their capacity to do so and an assessment of their best interests in line with the recommendations of the Dept. of Health (2001). However, on this ‘best interests’ issue alone Vass et al. (2003) argued that the Department of Health were ‘sitting on the fence’ by not going on to define clearly what they meant by the phrase. For example, in whose best interests is the research being carried out? Is it being carried out in the best interests of the people with dementia themselves and their care-staff, and if so how can this be best gauged and clearly defined within a protocol (Vass et al., 2003)? As a Dance Movement Psychotherapist, over and above the research governance framework, I was bound by a professional ADMP code of conduct and also by the Caldecott Rules within the



NHS. These rules make sure that researchers not cause hurt or harm to any participating patient or member of the care staff team and they also forbid the release into the public domain of any personal information that can identify people, especially patient's names, medical history, telephone numbers and contact details. I interpreted these rules in relation to this study meaning that they could also include, for example, tiring people out during the training or session days, the use of certain movements and or exercises potentially harmful for people with a heart condition e.g. not allowing both hands above the head for any length of time and full neck circling exercises e.g. not allowing rotations of the head a full three hundred and sixty degrees. Patients and care staff needed to be able to withdraw at any time from the programme if they chose, respecting their dignity, their rights, safety and well-being. I needed a full Criminal Records Bureau check described as 'Enhanced Disclosure' with accompanying paperwork in place before starting practical work on the programme. The fieldwork phase had received Chairman's approval (Appendix F) from a Health Authority Ethics Committee and the Academic Board of Roehampton University.

Traditionally, consent is given on the basis that the person is fully informed, that consent is freely given, can be withdrawn at any time and that the person is competent to give that consent. People with dementia involved in research projects present particular challenges, including difficulties with comprehension, dependency on others, memory loss and even an unawareness of the diagnosis. In spite of these challenges as Vass et al (2003) have also argued, there is an obligation to do good research in order to learn more about the dementia condition improving the care of

those affected which is at odds with the concept of carrying out research with people for whom 'informed consent' is deemed impossible. This represents a dilemma about being able to carry out research with people who cannot consent while at the same time protecting the interests of all involved and not putting anyone involved at risk. Following the work of Husband, Downs and Taster (2002 cited in Vass et al. 2003) there is also now a general understanding that consent needs to be on-going, rather than something that takes place only at the beginning or which is limited in time; thus there needs to be built into the programme continuing opportunities to discuss any concerns or for participants to withdraw at any time. During the study, regular care-staff meetings for session preparation and review were built-in, allowing any relevant issues including consent to be discussed during them. Patients were closely observed before, during and after sessions by staff that knew and worked with them to ensure that they were not attending or participating in any way that caused them stress or harm.

The consent procedure developed for use in this study was a three-stage one based on that pioneered by Allan (2001) who investigated how staff can enable people in their care to express their opinions and ideas. Having attended a workshop led by her in early 2001, I was better equipped to develop one for this study, based on her very thorough protocol. It involved the use of different coloured leaflets each with a similar purpose relating to obtaining consents from patients and staff but simplified and adapted according to who they were to be used by. The procedure for using with patients is described below. A similar explanatory leaflet and accompanying signed

consent form was developed for use with staff and again maintaining the idea that consent was a continuing process.

### **6.9.1 Consent Stage 1 – Involving the relatives**

This stage involved the relatives being given pink coloured information leaflets, their purpose to describe the study, what it was about and how it would be carried out. The use of video was referred to and information given about how and why it would be used and that anonymity would be protected. I was happy to talk with anyone on the telephone should there be any questions or concerns that needed to be addressed. Provided the relatives were happy and had no concerns about their relatives being approached to take part and knowing of no reason why their relative might object to taking part, they would be asked to sign the pink coloured relatives consent form that went with the pink leaflet. As relatives cannot in law give ‘proxy consent’, the emphasis in terms of consent has to shift to relatives having no objection, which is acceptable.

### **6.9.2 Consent Stage 2 – Talking to the patient**

A member of the ward staff team involved in the programme approaches the patient at a suitably chosen moment to talk with them about the study. A copy of the yellow leaflet, which is a simpler version of the pink one is used here, which also includes a photograph of me in the top right hand corner. The font size used is large enough so the type on the page appears larger and more readable and activities are simply described in terms of:

- ‘Listening to music’.
- ‘Moving gently to music’.
- ‘Sharing stories and memories and being able to reflect on our experiences’
- ‘Some singing and taking part as a member of a small group’
- ‘It will also include staff who work on the ward and who are known to you’

I introduce myself on the leaflet inviting them to take part. The staff member needs to be patient in working with the person to enable the information to be understood, emphasising that information will go to me the researcher and that it will be used to write up this study. This process may need to be repeated at least once. If the member of staff considers that the person is able to comprehend and agrees to participate they are asked to sign the yellow consent form. A copy needs placing in their nursing/medical notes and in addition the content and outcome of the conversation recorded in the patient’s notes as well. If the patient understands the project and expresses unwillingness to participate, in the opinion of the ward staff, then this should be accepted and also noted on their nursing/medical notes.

Lastly, in Stage 2 in the opinion of ward staff, if it is difficult to know whether or not the patient understands the nature of the project and the request to participate, but *does not* express anxiety in any way, then two members of staff should complete the blue form. This states that while it was not possible to determine the patient’s ability to understand, the intention is to proceed to the next stage, which is continuing consent and again this noted on the patient’s file.

### **6.9.3 Consent Stage 3 – Continuing Consent**

This final stage continues throughout the duration of the project and ensures that the rights, safety, dignity and observed well-being of all involved are maintained throughout (Dept. of Health, 2001). This stage also means that the purpose of the project is explained as and when needed, people are reminded regularly that there is a project going on and; they are still willing to participate without coercion or pressure of any sort. Anonymity was maintained at all times particularly in relation to the use of the VTR which was used under the following protocols:

- a) It remained the property of the participating Trust and was locked away when not used by the research team and RC.
- b) It was not shown publicly at any time and would be destroyed after the research period was complete.
- c) Names of patients, staff or any demographic information enabling them to be identified were not used. Patients and staff were given pseudonyms for data analysis and writing-up purposes.

## **Chapter 7 Analysis and discussion of findings**

### **7.1 Introduction**

The purpose of this chapter is to detail the analysis and discussion of findings in the three research areas under investigation and referred to in the previous chapter. These include the impact of the analysed session on people with dementia, the impact on the care-staff and the discovery of themes and meta-themes from which it was possible to draw conclusions. The chapter will first investigate the effects of the session on the well/ill-being of the group, followed by each individual as identified through the use of Dementia Care Mapping (DCM) methodology and Video Tape Recording (VTR/Appendix A) as detailed in Chapter 6. The chapter will then identify embodied practices and their impact on both group and care-staff. The impact of the session on the care-staff will be analysed in relation to questionnaires (Appendix D and E), followed by the presentation and analysis of the Themes (Appendix B) and Meta-Themes (Diagram 2) associated with the transcript of the VTR (Appendix A). The reflections on the fieldwork (section 7.7 onwards) will relate to furthering knowledge and understanding about the effects of DMP on people with dementia and their care-staff, with particular relevance to embodied, creative and therapeutic practices in improving communications, relationships and the quality of care practices.

### **7.2 Effects on observed well/ill-being of people with dementia participating in a DMP session**

#### **7.2.1 Dementia Care Mapping (DCM) Group Results**

The following two sections describe the results of DCM first on a group basis and

then in terms of individual patients. The methods used to undertake these tasks followed those described in the 7th Edition DCM Manual and the Computer Assisted Data Analysis Manual (Bradford Dementia Group, 1997 and 2002).

Table 1 (see below) shows Group Well/Ill Being(WIB) Scores which give an overall value as a WIB score for the three Before, During and After time periods identified both here in the mapping scores and tables and also cross referred with the VTR Transcript (see Appendix A). The figures in Table 1 are arrived at by aggregating the total WIB scores for the time period selected and dividing them by the number of five minute long time frames. If the person goes to the toilet the Behaviour Category Code (BCC) Code X will be used and this time frame and well/ill being (WIB) score will be ignored in the aggregated summaries.

**Table 1** **Group WIB Score**

	<b>Before</b>		<b>During</b>		<b>After</b>	
<b>Times =</b>	<b>9.40am to</b>	<b>10.25am</b>	<b>10.30am to</b>	<b>11.25am</b>	<b>11.30am to</b>	<b>12.00pm</b>
<b>Name</b>	<b>WIB</b>	<b>Time</b>	<b>WIB Score</b>	<b>Time</b>	<b>WIB Score</b>	<b>Time</b>
	<b>Score</b>	<b>Frames x</b>		<b>Frames x</b>		<b>Frames x</b>
<b>Martin</b>	<b>+8</b>	<b>8</b>	<b>+15</b>	<b>12</b>	<b>+7</b>	<b>5</b>
<b>Valerie</b>	<b>+9</b>	<b>7</b>	<b>+38</b>	<b>12</b>	<b>+11</b>	<b>5</b>
<b>Arthur</b>	<b>+7</b>	<b>7</b>	<b>+18</b>	<b>12</b>	<b>+5</b>	<b>5</b>
<b>Gladys</b>	<b>+21</b>	<b>9</b>	<b>+32</b>	<b>10</b>	<b>+18</b>	<b>6</b>
<b>Totals</b>	<b>45</b>	<b>31</b>	<b>103</b>	<b>46</b>	<b>41</b>	<b>21</b>
<b>Therefore</b>	<b>45÷31=</b>	<b>1.4</b>	<b>103÷46=</b>	<b>2.2</b>	<b>41÷21</b>	<b>1.9</b>

Results for the group indicate that with an aggregated WIB score of **2.2** out of a total of 5, the session can be seen to increase observed and relative well-being for the group in relation to what went before (pre) **1.4** and what came after (post) **1.9**. This is an important finding and consistent with the findings in the Perrin (1998) evaluation of the Crichton study (1997). There is also an indication here in Table 1 that during the ‘After’ period, there is a slight increase in WIB score compared with the time ‘Before’ the session. This indicates that well-being for the group has been sustained for a period of twenty-five minutes following the end of the session. This is significant as one could normally expect a rapid tailing-off effect after the completion of the session. This is also consistent with other findings using DCM (Perrin, 1998). These scores clearly indicate that DMP is having a positive effect on the group in relation to maintaining, supporting and increasing observed well-being for the session’s duration and also during the post-session period as well. These findings are generalisable in a wider context and one could expect to see a similar group WIB score profile in sessions of this type.

Table 2 (below) indicates the Group WIB Value Profile for the duration of the mapped period (Before/During and After). There were no WIB value scores indicating that any of the patients were in a state of ill-being indicated by scores of minus 1, minus 3 or minus 5. This is significant together with the fact that during the session the group were in a +5 score of ‘exceptional well-being’ (Bradford Dementia Group, 1997: 24) for 37% of the time and 30% at +3 showing ‘considerable signs of well-being’ (Bradford Dementia Group, 1997: 24), indicating that overall the session had a significant impact on the group when compared with before and after scores.



For an individual or in this instance the group to reach WIB score values of +3 and +5, is a significant indicator that they were experiencing high levels of observed well-being in relation to identified BCCs at the time. These high scores were mainly being recorded in relation to BCC ‘E’, which refers to creative self-expressive activity, and BCC ‘J’, which refers to participation in exercise, reflecting the impact and importance of the movement and exercise (embodied practices) elements of the session and noted in relation to Martin and Gladys. An electronic version of the original scores (Appendix C) was created from the raw data sheet from which these tables and charts were created, thus enabling a tie-back to the original score sheet.

**Table 2                      Group WIB Value Profile**

← Before →			← During →			← After →	
WIB %	Time frames x	WIB Value	WIB %	Time frames x	WIB Value	WIB %	Time frames x
0%	0	+5	37%	17	+5	0%	0
23%	7	+3	30%	14	+3	48%	10
77%	24	+1	33%	15	+1	52%	11
0%	0	-1	0%	0	-1	0%	0
0%	0	-3	0%	0	-3	0%	0
0%	0	-5	0%	0	-5	0%	0

For purposes of clarification, Table 3 (below) refers to a selected list from a total of twenty-four BCCs in order briefly to clarify and illustrate some of the definitions used in relation to them. Working definitions of each BCC are more detailed in the 7<sup>th</sup>

Edition Manual and this table is only meant to be a brief pointer to the meaning of the codes identified in this study. DCM is used to help care staff and others discover what people with dementia do with their time, the impact on them of any activity or in this case treatment medium and to identify gaps where a small range of BCCs may indicate that an individual's quality of life may be diminished or diminishing. Care staff suitably trained can and are using information like this, following a longer and more common eight hour map to identify and audit areas where a patient may benefit from a particular input or activity, which they are currently not doing. This may result in an overall improvement in their well-being once an activity, for example, can be found that was not previously a part of their care programme. As Brooker demonstrates, 'The method can feed into care planning since it highlights in clear behavioural terms what needs to be done to improve the quality of daily life for the dementia sufferer' (Brooker et al, 1998: 67). My particular focus however, was to use DCM to capture the effects on the person with dementia and the care staff in response to the session, rather than as an on-going developmental process or quality of care audit.

<b>Table 3 Selected List of Behaviour Category Codes</b>		
<b>Code</b>	<b>Memory Cue</b>	<b>Description of category</b>
A	Articulation	Interacting verbally or otherwise
B	Borderline	Being socially involved but passively
E	Expressive	Engaging in expressive/creative activity
J	Joints	Participating in exercise /physical sport
K	Kum & Go	Independent walking, standing or wheelchair moving
M	Media	Reading newspapers, watching television
S	Sexual Expression	Activities relating to sexual expression
X	Excretion	Visit to toilet/bathroom

Table 4 (below) details the other significant indicator and evidence for impact on the group relating to the percentage of time the group spent in each BCC. These scores were also significant indicating the range of activity for patients increased ‘During’ the session, compared with what was taking place ‘Before’. During the session as presented here, patients were involved in three more types of activity than previously, when sat in the main lounge of the ward including BCCs E, J and S. This is evidence for an increase in range of activity. Also, 58% of the time was taken up in self-expressive (E) and joint movements (J) of one kind or another. There is evidence here for the amount of creative and movement-based (embodied practices) activity as a percentage of the total. When placed alongside the VTR data from the transcript, it

enables me to differentiate the type of activity and range, also the impact of these activities on the group and individuals present and the relationships between them in order to draw conclusions.

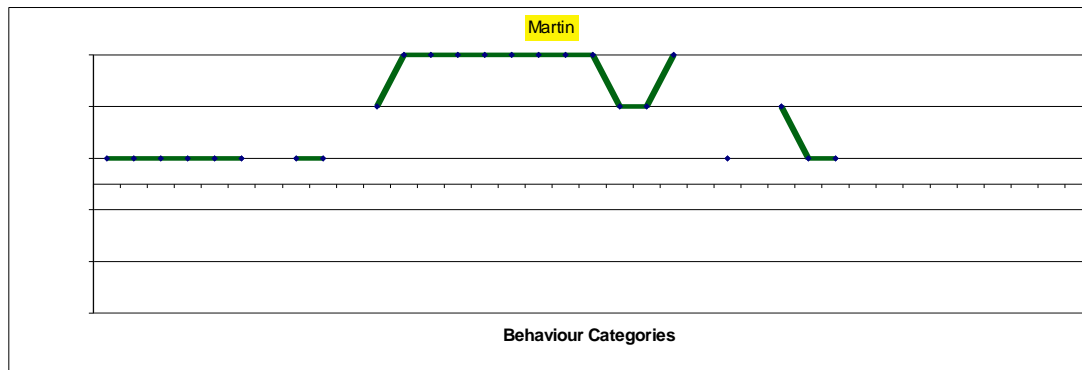
**Table 4 Group Behaviour Category Code Profile**

Before			During			After		
BCC	Time Frames x	% of time	BCC	Time Frames x	% of time	BCC	Time Frames x	% of time
A	6	16%	A	9	19%	A	6	25%
B	15	42%	B	6	13%	B	10	42%
K	9	25%	E	24	50%	K	5	21%
M	1	3%	J	4	8%	X	3	12%
X	5	14%	K	1	2%			
			S	1	2%			
			X	3	6%			

### 7.2.2 Individual Results – Martin

The raw data from the mapping process, used to create Tables 1 to 3 above, has here been used to create charts identifying the BCCs and the WIB value scores in relation to individual patients. This enables the impact of the session using DCM to be analysed in relation to them. Chart 1 (see below) was produced following the process described in the Computer Assisted Data Analysis Programme (Bradford Dementia Group: 2002: 15). Each blue dot on the chart represented a five minute time frame.

**Chart 1**

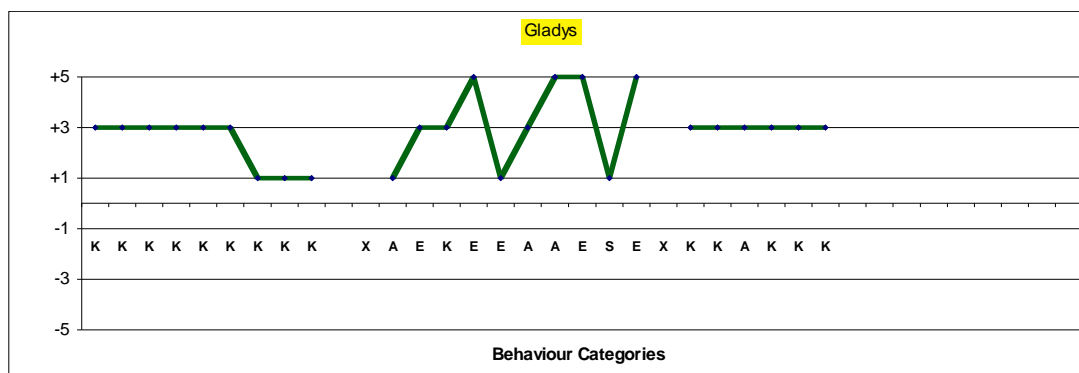


During the session, an older person called Martin with severe frontal lobe dementia, poor speech and a very poor short-term memory was enabled to make a connection, or 'bridge of understanding', between the music of Al Jolson and his own past memories. This contributed to maintaining his high observed well-being and gave the patient particular pleasure. Prior to the session 'Before', he spent 100% of the time at a WIB value score of +1 at BCC (B) that identified 'Passive Involvement' (see Table 3). During the session, 75% of the time was spent at WIB score values of +5 and 25% at +3 in BCCs (E) Expressive and (J) Joints. Post session, Martin went to the toilet and a five minute time frame (11.40-11.45hrs) was left blank on the raw data sheet (Appendix C). These scores clearly evidenced significant positive person work in DCM terms and the range of BCCs increased during the session by a factor of two, however scores alone are limited. Scores per se are impersonal and only tell a part of the story in relation to analysing the richness and complexity of the interactions and communications that took place. Analysis of the VTR data in a later part of this chapter will broaden and deepen the study of the impact of the session on Martin and the other patients.

### 7.2.3 Individual Results – Gladys

This session had a significant impact on Gladys in relation to analysis of the DCM scores referred to in Chart 2 ( see below).

**Chart 2**



Both Gladys and Martin spent periods of time in a +5 state of well-being with no indications of ill-being, however as Chart 2 reflects, the session itself saw quite significant changes for Gladys reflected by the peaks and troughs in the chart. What might be going on for Gladys to contribute to these peaks and troughs? Why did she not stay in a high state of well-being similar to Martin in Chart 1? These questions point to where the generalisable aspects of the session give way to the specific. Diverse factors including individual character traits, pharmaceutical, environmental and other influences were at work making them difficult to differentiate, analyse and generalise.

From analysis of the WIB Values and BCC codes it was possible to identify that prior to the start of the session Gladys spent 30 minutes in BCC 'K' referring to 'Kum and Go' and the activity of independent walking. To be given a +3 score here meant that Gladys was, 'walking while positively interacting with someone, or walking alone

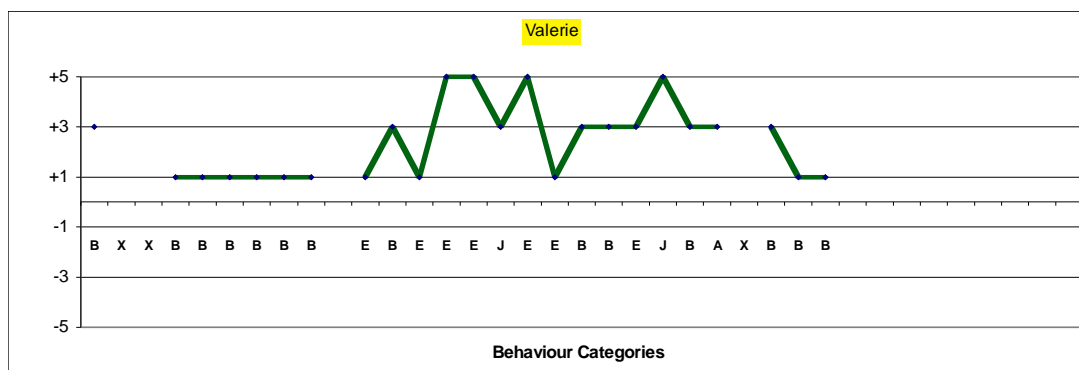
with great interest' (Bradford Dementia Group, 1997: 41). This behaviour was obviously important to her and lasted for a further 15 minutes although at a lower WIB Value of +1; a reduction therefore in the intensity of observed well-being and 'walking with small signs of well-being' (Bradford Dementia Group, 1997: 41). Walking was an important activity for her and this pattern of walking continued into the session. I found it particularly challenging to work with Gladys, as I considered it necessary to support her decision to move as and when she liked in the session. This meant I had to be constantly alert to Gladys's movement in and around the space, supporting, encouraging and mirroring it, whenever possible.

The start of the session for Gladys began with her going to the toilet, marked by an X on Chart 2. After this, Gladys took part in expressive, creative activities BCC E, engaged in interacting with others BCC A and also in relation to sexual expression BCC S. The range of her activities expressed as BCCs had increased prior to the session by a factor of three and so had her well-being as recorded by WIB Values. For example, Chart 2 recorded Gladys as having spent a period of 20 minutes ( 4 time frames) in a +5 state of, 'exceptional well-being – it is hard to envisage anything better: very high levels of engagement, self-expression, social interaction' (Bradford Dementia Group, 1997: 24). BCC S, was also recorded for Gladys and not for anyone else in the group. This was significant and recorded at a WIB value of +1, defined in the manual as, 'mutually agreeable small flirtations e.g. one participant being complimented and stroked on the hand by another and responded to with a gentle smile' (Bradford Dementia Group, 1997: 48).

### 7.2.4 Individual Results – Valerie

The DCM results for Valerie (see Chart 3 below) showed quite clearly that before the session she was socially involved but passively BCC B (Table 3 above).

**Chart 3**



Having recorded an initial WIB Value of +3 for a five minute period, which demonstrated strong interest in others it was followed by ten minutes for a toilet visit after which +1WIB value for thirty minutes recorded a ‘small degree of interest in others or the surroundings, but not taking direct part’ (Bradford Dementia Group, 1997: 32). During the session, BCCs also increased in range by a factor of 2 including BCCs E and J and WIB Value scores also increased from +1 for 30 minutes (prior) to + 3 for 25 minutes and +5 for 20 minutes (during). The increase in range of BCCs was similar to that observed for Martin and Gladys. The session clearly had an important post-session impact on Valerie, as her WIB Value score remained at +3 for a 15 minute period, before returning at 11.50hrs to BCC B and a WIB Value of +1 as it had been prior to the session.

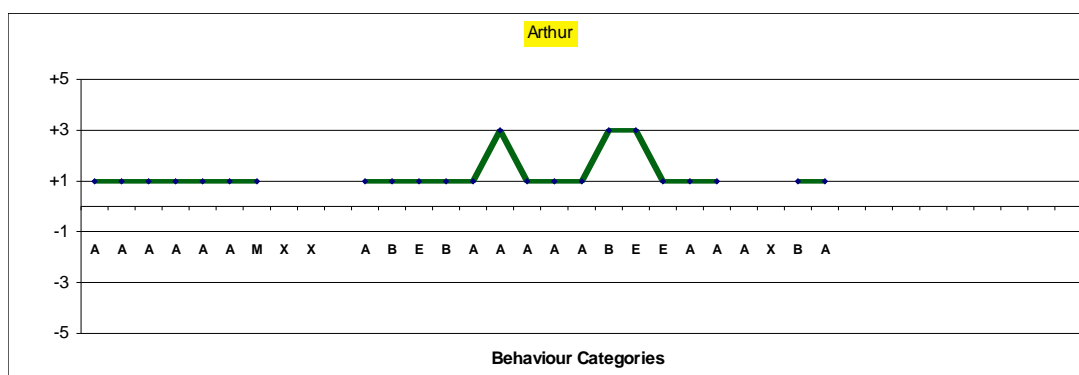
### 7.2.5 Individual Results – Arthur

Chart 4 (see below) recorded a different kind of DCM profile for Arthur, indicative of



a different kind of experience. Once again the range of BCC codes increased by a factor of 2, including BCCs E and B which was similar to other patients.

**Chart 4**



The WIB Value scores however were not as high as those recorded for Martin, Gladys or Valerie. Arthur recorded values of +3 for a total of fifteen minutes during the session. Interestingly ten of those minutes happened in the last fifteen minutes of the session which co-incided with his sudden moment of hymn singing that took me quite by surprise. I referred these scores for further analysis to a senior member of staff in the NHS Trust I currently work for, someone specially franchised as a DCM trainer. She pointed out that this pattern of scores and WIB Values indicated that Arthur obviously benefited from the 1:1 attention he received during the time when his WIB Values increased to +3. I found this comment very helpful as it raised the question, how could I in the session and staff afterwards, have helped sustain his well-being, as before and after those periods his WIB Value scores remained at +1? This indicated that the groupwork approach may not have suited his personality/temperament and that 1:1 working was more his preferred style for therapeutic work; or alternatively that the others in the group had inhibited him in some way? A conclusion one could draw on the evidence of the raw data scores, was

that Arthur needed more 1:1 support from staff, to enable him to make and sustain social connections between himself, others and his surroundings.

### **7.3 VTR Results**

#### **7.3.1 VTR Results – Martin**

The intention of the data analysis of the VTR (see Appendix A) was to broaden and deepen the study of the impact of the session on Martin and the other patients. During the session, Martin was observed using musical instruments, taking part in a movement activity using a circle of elastic, dancing with ribbons on sticks and in particular hitting a large drum with a stick very rhythmically:

‘Instruments have been passed around. Martin is using the rattle in his right hand. I hold a drum up in front of Martin and he starts tapping the drum rhythmically, quickly at a tempo of about 224 beats per minute continuing at this rate for about a minute’ (Theme 4b, Appendix A, 10.50am).

Significantly, Martin would not normally have taken part in these kinds of activity on the ward and the intention of the training and development programme was to introduce them and make them more available to patients and staff. This raises the question of their relevance to Martin in particular and people like him. As recorded above, Martin is clearly engaged in this rhythmic activity and close inspection of the VTR revealed his obvious enjoyment of the experience. Couple this with evidence for Martin’s repeated shaking of my hand at the beginning of the session (10.25am), his rhythmic foot tapping (10.40am) and a pattern begins to emerge of a person who

gains particular pleasure from sensory based (Kinaesthetic and Aural) experiences, notably rhythmic movement. For a person with limited cognitive ability, this is clinically revealing and important as being of obvious support to him, as cross-referenced by the DCM scores that also recorded high well-being scores at this time. Theoretically, I was able to make a link to an important theme in DMP relating to the importance of rhythmic movement and the work of Chace (Chace, 1975) that I have referred to in Appendix A as Theme 4b 'Importance of rhythmic movement'. Also of significance was my discovery of the importance of the music of 'Al Jolson' to Martin and the following dialogue that revealed it here:

'LC: Martin, what's your favourite song? Your song, what did you used to sing on a night when you used to go out clubbing? With Winnie. Theme 5b and 8

RC: Did you go dancing Martin?

Arthur: Blackpool Theme 9b.

Martin: Johnson? →

(.....)

RC: Johnson? Theme 10and14

Martin: Al Jolson

RC: Al Jolson. Would you like to hear some Al Jolson? Wow, fantastic. I wish you'd said. I could've got that out sooner.(Theme 6 and 15) I love Al Jolson, he's one of my favourites. Here we go' (Appendix A, 11.10am).

This section of dialogue is confusing at first glance. Taken out of sequence and context the communications may appear 'vague', 'fragmented' and 'uncompleted'

(Nyström and Lauritzen 2005: 302). The dialogue reported above took place in the 11.10am time-frame that coincided with Martin scoring a +5 WIB score in BCC 'E'. It was not immediately apparent here, but for the first time in the session, Martin was able to say words that were audible and intelligible in relation to his appreciation of the music of Al Jolson. At first I heard him say, 'Johnson' which I then repeated back to him. He then repeated 'Jolson' and so I was able to correct my initial assumption he was referring to 'Johnson'. I could not contain my excitement at this moment, which I recognised as significant in relation to what I had previously known and experienced in relation to Martin. Significantly, it was only once I had begun to analyse the VTR that I was made aware of my being critical of him not telling me sooner. The VTR had given back to me a moment that would otherwise have been lost to memory; subsequently re-discovered and remembered, it became an important learning opportunity for me. This moment was also witnessed by a staff participant (GB), who immediately stood up and moved across the room to dance with Martin, once I had responded to it by putting on some Al Jolson music, which he very much enjoyed.

### **7.3.2 VTR Results – Gladys**

Analysis of the VTR Transcript (Appendix A) alongside the DCM data has proved invaluable in studying the impact of the session on patients and none more so than on Gladys. She had spent much time walking around the main lounge prior to the session starting (BCC K) and this need continued during the session. I recognised this need, non-verbally and consciously, and responded to it by making it possible for her to walk around the room and, even leave it accidentally, as a door was left open to an

adjacent ward. This was a mistake in the pre-session preparation period and the door should have been closed by me. At this point, 10.50am, I had to leave the room in order to bring Gladys back to the lounge we were using. It was a difficult moment and while VTR made it significantly easier to record and analyse dance sessions, the shortcomings of having only one camera meant that it was difficult to record the whole session in its entirety; therefore, as in this instance, some evidence was missing (Palo-Bengtsson, 1998: 19). I asked her directly if she would come back, I remembered her saying ‘Why?’ and being for a moment non-plussed by this reply. I remembered answering, ‘because I like you very much Gladys and I would like to dance with you again in there’ (referring to the lounge we had left). She said, ‘alright then’, and I was able to escort her quietly back to the session. It was a moment of relief for me, as it is never advisable for the psychotherapist/facilitator to leave the room once a session had started. The psychological as well as the physical space needs to be well contained, otherwise the energy can dissipate and the group fragment in the context of the session taking place in a safe, non-threatening and psychologically contained environment.

Another significant moment was when Gladys was fully engaged in dancing with me while music was played including the use of maraccas and other musical instruments used by session participants. Here is the extract from the the VTR transcript, 10.50am:

‘As this song is sung and instruments played I am holding Gladys’s hands and rocking side to side with her in the middle of the circle.

She makes strong eye contact with me. Gladys moves to the side of the circle as if to leave the group then says something quietly – I motion to the rest of the group to stop playing instruments so I can hear what Gladys is saying to me very quietly.

‘Gladys: I enjoy you all working.

RC: You enjoy working Gladys.

Gladys: Mmmmm.

RC: Oh, thank you for that. I think you’re lovely Gladys. Did it remind you of any songs?

Gladys: Yes, all of Grandad’s

RC: All of grandad’s. Ahaa. Yeah, Aaah.

Gladys: Lights, what are you?’

Gladys had appreciated the hand-holding and dancing very much and said here, ‘ I enjoy you all working’. I interpreted and understood her to be *meaning*, ‘I have appreciated you all and what we have just done very much’. Here I was working quickly, in real-time, upper-most in my mind the need to respond appropriately and without delay. I then repeated this phrase back to her implying, ‘and you enjoy it too Gladys!’ attempting to verify her meaning. She responded in the affirmative, ‘Mmmmm’. Here also was evidence for my attempting to make a ‘bridge of understanding’, between the known (what we had just experienced together) and the not yet known (the meaning of her words) as I attempted to make sense out of them. During this time-frame Gladys was engaged with me in expressive activity (E), was clearly in a high state of well-being, making strong eye-contact, together with

evidence of the spoken dialogue above. Once into the following time-frame at 10.55am where the WIB score went down to +1, there was more of a focus on dialogue with Arthur in the transcript. There was no VTR evidence unfortunately of what Gladys was doing. From memory, I think she was sitting in her seat across the circle not really participating in the foot-tapping exercise to scottish music.

Towards the end of this latter time-frame I noticed Gladys's subdued behaviour and deliberately moved towards her, kneeling down on the floor and trying to think of a song I/we could sing to her, by way of bringing the focus of the session back to her. I decided at the time that this was on balance the best approach, having ruled out other considerations, for example that she might be in some discomfort physically or emotionally. Once the focus of the session was back on her again through song, I would argue it was the trigger for Gladys moving back to a relatively higher WIB score value (+3) for the time frame beginning 11.00am. Significantly, as a result of detailed analysis of this section of dialogue and behaviour, I concluded that Gladys was like Arthur, a person who needed and benefited from, individual one-to-one attention and support. Once that one-to-one attention and support was withdrawn or removed, for whatever reason, her observed well-being dropped and here we have the evidence for it. This behaviour and the recognition of it, was important as it contributed to maintaining her overall well-being. From a clinical practice perspective, I would also argue that if Gladys's well-being was to be maintained longer term and outwith the session, the provision of more one-to-one attention would support that outcome.

There is one other moment I would like briefly to discuss in relation to Gladys. It illustrates that however confused a person with dementia may at first seem, there may remain potentials, skills and abilities that confound and surprise with their immediacy, quick-wittedness and humour. I had selected a song to sing to Gladys that I knew well and that I thought she would like, in the context of finding ways to engage creatively with her, other than through movement and dance, although music, movement, dance and song are closely linked. The song came from musical theatre and was sung originally by Fred Astaire. It is called 'Cheek to Cheek' with words and music composed by Irving Berlin. The extract below describes this moment:

RC: starts singing a music hall song 'Cheek to cheek': 'Heaven, I'm in heaven and my heart beats so that I can hardly speak and I seem to find the happiness I seek'...small gap in filming here... 'Heaven, and I love to climb a mountain and to reach the highest peak, but I don't enjoy it half as much as dancing cheek to cheek'.

RC: 'Dance with me I've got my eyes about you'.

Gladys: Yes, I know.

RC: 'My heart about you, so dance with me please'.

SD (off camera) to Gladys: What do you think of it?

Gladys: I love it.

RC: 'when we're out together dancing, out together dancing, out together dancing, when we're out together dancing cheek to cheek'

(Appendix A, 11.05am).



Here Gladys is stood next to me while I'm singing directly to her and seated in my chair as in Diagram 1 (Chapter 6.6). Quick as anything she responds to my 'Dance with me I've got my eyes about you', with ' Yes I know !'. At this point the staff hear the comment and laugh briefly and I'm so caught up in trying to remember the words of the song I don't really hear her response, or if I do I am not consciously aware of it. Once again the analysis of the VTR was surprising for me as it highlighted this small and intimate moment, illustrating that, there can be moments of clarity and quick-wittedness defying logical explanation in relation to high levels of confusion otherwise evident for Gladys.

It is possible to generalise here that as psychotherapist/facilitator, we must be ready to be surprised by the quite extraordinary moments of insight and clarity that can occur at any time during a session. Also in this small section of dialogue Gladys was asked by a member of staff what she thought of it and she was able to say, 'I love it'. We thus have clear evidence from Gladys herself, in her own words, regardless of what any Dementia Care Mapper was seeing and recording, that what was taking place was of great significance to her, given her vulnerable and frail state. This was another example revealing a level of complexity in human interaction and behaviour taking place in the session that I was not at the time aware of, even though other participating staff were and arguably I should have been?

### **7.3.3 VTR Results – Valerie**

The transcript (Appendix A) refers to Valerie moving gently from side to side while music was played during the 10.25am time-frame at the beginning of the session. These were movements in range and quality that Valerie was to repeat throughout the session. It was clear through repeated watching and analysing the VTR that they gave her particular pleasure. In the 10.50am time-frame Valerie was again seen moving side to side and also using a shaker in her right hand. She appeared to be breathing deeply and I was aware of the need in response to this to do my best to ensure that the physical activity involved in the session was not too tiring for her or anyone else in the session. Here also was evidence for my ‘building bridges of understanding’, between my impressions or assumptions relating to how people were coping with the physically tiring or embodied aspects of the session and the real-time experiences of the patients directly involved. How were they coping, were there signs of breathlessness as with Valerie and should the movements be stopped in response? There was a constant need for me to be able to read the signs of any distress, or discomfort in particular and ensure at all times that the practices were safe. I would argue that I was able to achieve this clinically and professionally during the session.

During the session Valerie can also be seen using ribbons on sticks during the 11.05am time-frame and in the last time-frame at 11.25am using a scarf to improvise while dancing with LC. In retrospect I did not spend as much time with Valerie as I would have liked. There can be patients like Valerie during a group session that for any number of reasons can fade into the background of the session. During this

particular session, I would argue that my attention was distracted by Gladys's constant walking around the room and my need to pay particular attention to that. This aspect illustrates the complexities involved in adequately identifying and subsequently meeting everyone's needs in a group session.

#### **7.3.4 VTR Results – Arthur**

Each patient responded differently to the session which analytically made the results diverse, rich and rewarding in their detail, Arthur was no exception; his DCM scores had previously revealed that during the session he had two episodes of scoring WIB Values of +3 for 25% of the session time. VTR analysis revealed a person somewhat distant from the embodied movement based practices that took place and that other patients valued.

Early on in the session (10.25am), when I put out my hand for him to shake, he sat on his own hands and looked away across the room withholding eye contact. I understood this to mean that he was demonstrating non-verbally and through his body his lack of interest in me and perhaps the session? During the 11.00am time-frame for example, he nodded his head left and right to me as I attempted to hand him a ribbon-stick to use. This I interpreted as meaning 'no', he did not want to participate in this activity. Also at the 11.05am time-frame, Arthur was not singing like everyone else, not engaged in movement activity going on around him with Valerie and the group, who were moving their ribbon-sticks up and down. In contrast Arthur at this time could be seen 'looking intently at something on the floor, tambourine in hand' (11.05am).

In spite of this observed reluctance at times to take part in the embodied practices, Arthur did not choose to leave the room. There was clearly enough going on for him to remain interested and for him to stay in his seat. As I sat next to him it was possible for me to carefully notice his body language and his reactions both verbal and non-verbal and to interact with him quite easily which I did fairly often. VTR analysis also illustrated that throughout the session he took in what was being said verbally and this had a particular interest for him. Not only this, he also heard words people used and responded to them once he had thought or considered them in his own way. As this took several seconds, his response, often came out unsynchronised within the current context or flow of communications and relationship. I was unaware of this time-lag in his communications at the time and only through the VTR analysis was it possible to analyse and repeatedly play those moments over again.

I specifically identified them under the Theme 9b 'Differing Narratives' in the transcript (Appendix A). One example was in the 11.15am time-frame: when Martin was asked if the display of ribbons and instruments on the floor reminded him of anything, Arthur answered saying in a questioning way , 'Colour, ribbons?'. The dialogue that followed between Arthur and me, involved him repeating the word 'coloured' as if he kept thinking about it, while I was attempting to make sense of what he was saying, asking at one point if he had said the word 'Scotland'. At the end of this section I said 'thank you' to Arthur and shifted the focus of my attention away from him and across the room to Gladys.

I was interested in this apparent delay in Arthur's communications with others. I

considered that it could be construed as evidence of his confusion, or of his indifference towards others and the therapist/facilitator. It could also be his simply taking a while to hear, process and respond to verbal communications, putting him as a result at odds with the normal ebb and flow of communications in the group. Equally, it could indicate that Arthur should really have been in a 1:1 therapy situation outwith the group. These were difficult problems to analyse, as there were many variables in unpicking and differentiating the constituent parts, as I attempted again to 'build bridges of understanding' between the known and the not-yet-known. What has emerged for my part is a greater awareness of this phenomenon of what I could describe as a 'processing delay' in communications that was difficult to be aware of and attend to during the ebb and flow and complex dynamics of the session. This has resulted in a change in my own awareness; I am now more open to the possibility of this phenomenon taking place in my current DMP clinical practice.

#### **7.4 Identifying embodied practices occurring during the session and their impact on both people with dementia and their care staff**

The non-verbal embodied area of work analysed and discussed here is founded on the premise that given the speech, word finding and other difficulties experienced by people with severe neurological insult, embodied practices can make an important contribution to improving communication and relationship. It is vital, therefore, that psychotherapist/facilitators are helped to pay better attention and respond more effectively to non-verbal embodied states of being and behaviour, in this relatively new area of clinical practice, research and study. I have previously referred to

‘embodied practices’ and their importance and meaning in this context in Chapter 3. This section therefore is an attempt to explore what embodied practices mean at the group and individual level in the context of the analysis and discussion of the data presented here and in the appendix.

#### **7.4.1 Identifying Embodied Practices at the group level**

This section aims to identify embodied practices taking place at the group level to highlight their importance in our being better equipped as psychotherapists and care-staff to work more appropriately and skilfully with frail, disoriented older people with dementia who find it difficult to communicate.

Methodologically, the session was transcribed with reference to audible dialogue (Words), Body Movement and Music, staying as close as possible to the VTR (the original data source). Following transcription, I analysed the dialogue, body movement and music and the relations between them. At first I felt my way into the process and gradually there was ‘emergence’ (Cambray, 2006) of phenomena that I subsequently identified and was able to reduce into thirty-three different yet complementary themes. Where the phenomenon investigated was seen for the first time, the theme was given a suitable name and number; where it recurred, a link was made to the previous theme and number that related most closely to it. These names and numbers were added to the transcript in red. Theme names were changed during the process if I thought there was a better way of describing the phenomenon. For example, Themes 9a and 9b had initially been grouped under one theme with the name ‘Logic Disappearing’. This name was not specific enough for describing the

complexities of what I was seeing in communications between Gladys, Arthur and me. I realised the phenomenon was more about narrative than disappearing logic. There were two narrative processes taking place that needed to be clarified, that I later identified as ‘Complementary’ 9a and ‘Differing’ 9b Narratives. This change meant that I was better able to understand what I was seeing and interpret its complexity more accurately. Resulting themes and their frequency of occurrence were then added together and a new table created (Appendix B, ‘Differentiating the VTR transcript themes’). This second, ‘reductionist’ process meant the themes could be rated in order of occurrence, together with their relative significance in relation to their frequency of occurrence; the greater the frequency of occurrence, for example, the more significant the theme.

The themes listed in Appendix B were used first of all to identify embodied practices at the group level and then to rate their order of significance. Extracting embodied practices from Appendix B has resulted in the following list (Table 6). More detailed explanations for the embodied themes listed in the table can be found in Appendix B and will be incorporated and described in more detail in a section below:

**Table 6**

<b>Theme No:</b>	<b>Embodied Themes</b>	<b>Frequency of occurrence</b>
18	Physical mobility and exercise	24
4b	Importance of rhythmic movement	22
21	Use of Dancing	19
14	Working with fragments	13
5a	Importance of singing	12
19	Use of props	10
3	Embodied Connections: eye contact	6
2a	Inclusion/exclusion	6
16	Spontaneous expression	4
1c	Embodied connections: height levels	4
1e	Embodied connections: hand holding	3
20	Use of instruments	2
1d	Embodied connections: body memory	2
2aa	Walking around room	1
1a	Embodiment well supported	1
1b	Embodiment not well supported	1

My analysis shows that embodied practices at the group level have played an important part in the session, particularly in relation to the three top scorers, relating to ‘physical mobility and exercise’, ‘rhythmic movement’ and ‘the use of dancing’. From a phenomenological perspective, the table is important in highlighting the main embodied practices according to their frequency of occurrence.



Dance and dancing as embodied practices listed in Table 6 are essential to the work of the Dance Movement Psychotherapist and the table has shown the importance of dancing, as it was one of the three top scorers. In Coaten and Warren (2008), I discussed the importance of Dance on developing self-image and self-expression through movement and in particular the link between movement and emotion: ‘The movements we initiate, the body shapes we form and the responses we present to external stimuli usually reflect our inner emotional state. The way we move, the way we stand, our gestures, all express (sometimes more accurately than the words we speak) what we feel at any given moment’ (Coaten and Warren, 2008: 64). The work of the psychotherapist/facilitator is to be able to understand and interpret these embodied communications and emotions and use them well in the practice of caring and building relationships with a person with dementia and vice versa.

Movement and Dance, including rhythmic movement and physical body-based exercises, are the building blocks for helping support embodied practices; nevertheless, embodied practices taking place outside of a dance movement psychotherapy context are also very important. We need and use our bodies at all times, not only while we are dancing, hence my main focus in this analysis is on the widest possible attention to what embodied practices are and what they mean.

These results were consistent with similar research of this kind (Coaten, 2001, 2002, Crichton, 1997, Donald and Hall, 1998, Gräsel et al, 2003, Hatfield and McClune, 2001, Hill, 1999, Meddaugh, 1998, Nyström and Lauritzen, 2005, Palo-Bengtsson, 1998, 2000, Perrin, 1998, Shustik and Thompson, 2001, Zachow, 1984) supporting

the importance of embodied practices in creative and therapeutic work with people with dementia that could arguably be generalisable to other groups and settings. Gräsel et al (Gräsel et al, 2003) in their overview study in Germany on non-drug therapies found that DMP can be used in a wide variety of stages of dementia. Empirical studies without control groups showed that in mild to moderate stages it was possible to target balance, mobility, strength and stamina.

In contrast to the rhythmic movement and dancing, Table 6 also lists equally important sophisticated and subtle embodied practices, what I've called 'well supported' and 'not well supported'. Theme 1c above (Table 6) refers to the importance of height levels and kneeling or squatting down to reach the eye level of the person being communicated with, in order to facilitate communication and relationship. Theme 1e, points to making contact non-verbally by holding a participant's hand in an aware and sensitive way. Both are examples of 'well supported' embodied practices. Theme 1b in contrast referred to a patient being moved in their chair by care staff, without the patient being consulted. These 'unsupported' embodied practices can as a result have a detrimental effect on the patient and should be avoided.

#### **7.4.2 Identifying Embodied Practices at the individual level**

'We see with more than our eyes, touch with more than our hands, hear with more than our ears and love with more than our hearts' (Zachow, 1984: 19).

This section aims to identify embodied practices taking place at the individual level to highlight their importance in our being better equipped as psychotherapists and care-staff to work more appropriately and skilfully with frail, disoriented and often non-communicative older people with dementia. The quotation above was taken from a detailed and evocative description of the author's work in the United States with a severely confused older person with dementia called Helen. 'Ninety-percent of the communication between Helen and me was non-verbal; we spoke with our bodies' (op.cit.: 20). In order to reach Helen the author used a variety of embodied pathways including sensory stimulation, relaxation, guided fantasy and music. Sensory stimulation included work in the following channels: auditory, visual, olfactory, body language and tactile stimulation including face massage. After eight weeks of intensive work Helen was reported as having been quieter, more alert, she fed herself consistently, responded verbally more frequently and well and slept the entire night. Medication had been reduced by fifty-percent in consequence. These are important findings, although they relate only to a case study on one person. They show how embodied practices that focus on the lived body can make a difference to the range, quality and outcomes of patient care, especially in relation to improving communication and relationship. The above quotation also sets the tone here for identifying embodied practices and their impact on those taking part in this study.

#### **7.4.3 Martin**

The session was very important for Martin non-verbally and particularly in relation to observed episodes of feet tapping (10.55am), tapping rhythmically on a drum

(10.50am), using ribbon sticks (11.05am) and dancing with GB while the music of Al Jolson was playing. All these were important embodied practices for him, which he can be observed enjoying very much, in spite of very limited language and verbal capabilities. Martin can also be witnessed tapping his hands on his knees, which is another significant form of embodied practice (10.55am) and at 11.10am his eyes were described as being 'very alert and wide' in response to his having danced with GB. While these moments could be seen as insignificant, they have to be placed in context that Martin is fairly consistently being rated as scoring at a +5 level on the DCM methodology by a mapper who as Deputy Unit Manager knows the patient well. They were significant achievements for a man with such poor ability to communicate his needs verbally, while at the same time needing those around him to be able to make sense of his communications non-verbally and in embodied ways. This session and the two previous ones were very important for him and as therapist/facilitator I was able to recognise that Martin used body movement to symbolise what he was unable to say. For example, the transcript highlighted a moment at the beginning of the session when Martin shook my hand vigorously (Theme 1d /Table 6) on meeting me and would not let go. I interpreted this as meaning he both recognised and valued my presence in the room at that time regardless of anything else going on. This was a significant example of an embodied connection made between us.

#### **7.4.4 Gladys**

Throughout the session Gladys was on the move; she clearly demonstrated that

embodied practices were very important for her, at times in her chair, at times moving across and round the outside of the circle and on one occasion leaving the session entirely to walk down a corridor. She really enjoyed dancing with me and these were session highlights for me, when I was able to get down to her level, make eye contact (Theme 3 /Table 6) and dance with her in the centre of the circle often by holding both of her hands (10.45am and 10.50am and 11.00am). It was also at 10.50am that Gladys expressed her emotional experience with me by kissing my left cheek which I registered as a strong emotional expression. At 11.10am she can also be seen rocking from side to side with MM. There was no doubt in my mind that embodied practices were of great importance to Gladys, especially being enabled and supported to walk around the lounge whenever she wanted to and in whatever way, sometimes interacting with other people, and singing, sometimes using props and instruments. Regardless of whether or not her constant need to walk around the room was in part a response to or side-effect of her medication, she needed to be able to do this and as psychotherapist/facilitator it was important that I recognised this embodied need and supported her to maintain it. It meant that my attention was constantly drawn at times away from the group and onto her and what she was doing.

#### **7.4.5 Valerie**

Valerie took part in all the group's activities and there was VTR evidence of her rocking from side to side in time with the music (10.25am), again when using a shaker in her hand (10.50am) and also when the Scottish music was playing (10.55am). Valerie also very much enjoyed using the ribbon stick (11.05am), moving

it up and down and moving from side to side at the same time. She also really seemed to enjoy using a scarf (11.25am). Valerie was seen responding well to embodied practices including rhythmic movement and dancing. This indicated a propensity to valuing embodied practices which by contrast was not shared by Arthur. Valerie also scored significantly high in her DCM scores (+3's and +5's) compared with a +1 score prior to the session starting.

#### **7.4.6 Arthur**

Detailed analysis of the VTR transcript has made me aware of what I have described as on-going narratives by patients. These significant individual narratives described as Theme 9b 'Differing Narratives', took place at least 22 times in the session. They happened regardless of whether or not I as therapist/facilitator was aware of or attentive to them. The analysis has helped to reveal that they were taking place and how important they were for the individuals concerned.

Arthur, for example, on the VTR can be observed as uninterested in the session at certain points, especially at the beginning; his body posture hunched over, while sat on his hands; at other times he can be observed picking up on words, actions and behaviour made by other participants that animated and interested him. His often delayed response I interpreted at the time as being somewhat typical of his lack of interest in the session and evidence of his confused state. I did not always give his communications the attention they required and neither was it easy to understand the context, the content or the delay in his responding to me (11.20am).

Arthur also had a tendency for delay in his response to session context, content and communications, sometimes over a period of several seconds. This explained, perhaps, why he spontaneously started singing a hymn towards the end of the session. At the time his decision to sing was both surprising and exciting to me as therapist/facilitator as it represented a significant contribution from him. Further analysis has helped put Arthur's spontaneous expression into a context of him being touched metaphorically and symbolically by what we were doing previously, and physically by LM who held his hand immediately prior to his singing. This contradicted my initial assessment and assumption of his being uninterested and rather uninvolved at the time. I was slow as a result to change my initial perception in response to the subtle nature of his embodied and verbal communications. I would argue that LM's holding of Arthur's hand as an embodied practice (Theme 1e) immediately prior to this hymn singing was very significant and acted as a trigger for him to be able to sing quite spontaneously. This was what Ward has described as the vital importance of effective communications going to, 'the very heart of who we are and who we want to be' (Ward, 2002a: 33); taking on in the process far greater importance than simply meeting a set of individual needs.

Also from an embodied perspective it was difficult throughout the session to have or maintain any kind of eye contact with Arthur. It was significant, however, that he took in a lot of what was happening in the session and was able to respond to it. As he was reluctant to hold my hand at the beginning of the session (10.25am), or onto a ribbon stick also offered by me (11.00am), it became clear that Arthur was not inclined to movement-based activities. He had instead a preference for responding to

the world around him more visually and verbally than non-verbally.

I have described Theme 9a as ‘Complementary Narratives’ meaning that there were occasions when two or more people’s narratives were taking place simultaneously and influencing each other’s communications as a result. These took place on at least three occasions and although few in number indicated just how much attention was being paid by Arthur and Gladys to each other’s verbal communications. The ‘Complementary Narratives’ I have described here and in Appendix B are significant and similar to what McMillan has called the ‘webs of interlocution’ or ‘the networks of interpersonal relations that we are immersed in, which play an important part in our formulation of a sense of self’ (McMillan, 2006: 67). McMillan also writes eloquently about the importance of narrative in the creation and maintenance of our identity and self-concept. For example, at 11.05am Gladys says to someone off camera, ‘Oh how dare you?’. Arthur without looking up at Gladys hears this and thinks it refers to him, at which point he says ‘How dare I?’. MM then says ‘Darling, how dare we what Gladys?’ followed by GB replying with ‘Go fishing?’. Arthur then says, ‘No, not go fishing’. If McMillan is right in his argument, then here described are the ‘networks of interpersonal relations’, that support our identity and sense of self, that are threatened by the dementia condition. The concept of ‘Complementary Narratives’, referred to here, I have also seen in my recent clinical practice where for example Sarah Jane Loxley uses narrative to describe her situation in a symbolic and very important way, supporting her identity. I have described this phenomenon previously in Chapter 2.



## **7.5 Identifying the impact of the DMP session on the care staff**

I have attempted to identify the impact of the session on the care staff with regard to several data sets including Appendix A and B, together with the analysis of two sets of questionnaires that related to assessing the impact on patients and care staff of the overall training programme (Appendix D and E). Appendix B has proved just how important the staff contributions were to the one analysed session on 17th April, with thirty identified staff contributions to the session and the highest frequency of occurrence identified under Theme 5b. Contributions from all participating staff were important in giving staff the confidence to value their own stories, their life experience and to help build better relationships with those in their care. This also contributed to development of their own skills (Meta-themes Diagram 2 below). As group facilitators they learned a lot more about their patients/residents than they might otherwise have done in the care home or ward context alone.

It could be argued that these results were to be expected with an overly high ratio of staff to patient at six-to-four respectively. A more usual ratio would be two staff to four patients. Arguably, this could have skewed the resulting data, placing more emphasis on staff and their impact than might otherwise have been the case. Also, on reflection, this raises the question about whether or not the DCM scores would have been as positive with fewer staff ? Investigating the communications and behaviour that gave rise to Theme 5b, has enabled me to know in some considerable detail what care staff actually did during the session and the impact they had. The analysis is particularly relevant in generalising these findings to other sessions of this type,

regardless of the fact that here staff numbers were high.

Care staff assisted patients into and out of the lounge and in to and out of their seats, they sang and moved and contributed to facilitating patients communication and relationships, verbal and non-verbal throughout the session. They also initiated songs and dances with patients and they used props. They also brought to the session an awareness of individual patient's needs that was a vitally important element and difficult to quantify, an awareness that, I would argue, helped contribute to the success of the session in terms of raising well-being and facilitating participation, communication and relationship. From my own observations these staff contributions demonstrated a growth in confidence, capacity and understanding and awareness of what to do and what not to do in relation to the provision of these DMP sessions. The programme has enabled more staff to access, witness and participate in the work and approach than might otherwise have been the case. From this training and development perspective, I would argue valuable lessons can be gained and learned from how staff responded. The questionnaires were designed and analysed with that in mind.

The 'Ongoing Evaluation Questionnaire' (OEQ Appendix D) was designed and developed by me and given to care staff after the arts based training day and initial session which had taken place on the 2nd and 3rd April 2002 respectively. It set out to identify the initial impact of the work and approach on the care staff, and contained a variety of different questionnaire formats. These included: self-evaluation, sentence completion, scoring (Likert Scale), prompts and goal setting. The OEQ was split into

two parts. Part 1 contained three related questions and Part 2 just one, relating to goal setting with accompanying prompts. The OEQ was not a complicated questionnaire and was designed for easy use and completion by Health Care Support Workers and Nurses. It was designed to capture early thoughts and feelings, following two significant training programme events. I was interested to know what impact if any the programme was having on participating staff. Sixteen copies were handed out and eight returned anonymously. This represented a return rate of fifty-percent. They were printed on pink paper to make them more noticeable in a folder.

**OEQ** – Question 1 asked, ‘What would you do differently as a result of what we have done?’

Answers were analysed and categorised under five headings:

- 1) **Caring more about the patient** – need to spend more time with them as distinct from more time in a task-oriented way – changing attitudes positively towards the provision of activities.
- 2) **Gaining new ideas** –especially about the use of props and resources and music ( scarves/balloons)
- 3) **Need for improved session planning, preparation and de-briefing.**
- 4) **Emotional impact** – “like seeing happy smiling faces’ – making the ward more pleasant through communication and touch.
- 5) **Future benefit** – a sense that the work and approach could benefit patients in the future

Analysis of these answers and others in the questionnaire pointed to participants gaining a greater awareness of, and more interest in, the individual people with

dementia in the group setting; in other words discovering more about them. Also evident was a sense of enjoyment and surprise about the work and its impact both on patients and clients and the participating care staff. Above all perhaps, there was an over-riding sense that the work and approach had been of value up to that point. This quote was one such example, referring to effects on the group: ‘During the session I saw people that seemed scared and frightened at the start, really enjoying themselves at the end’ (Appendix D). This comment indicated that this participant was aware of quite significant change taking place in relation to a lessening of fear for those patients observed. Also the Part 1 question, ‘Effects on Clients?’ showed that ‘Maintaining contacts in isolating situations?’ was scored the highest by the care-staff. This indicated that the care-staff were aware of the isolating nature of the dementia condition and that this programme had contributed to lessening it for the patients. This also reflected the value of individual patients still able to make and maintain some kind of social contact with other people on the ward. The work and approach here described was according to the care-staff having an important outcome on the patients. I would argue this awareness as referred to in the OEQ’s was important evidence of the care staff demonstrating increasing capacity to notice more about the impact on their patients.

Overall, in relation to the OEQ, I would argue that here was clear evidence for a growing interest in the work and approach, in response to the training day and practice session reported on by the care staff. Growing awareness of and interest in this work are, I would argue, essential elements in developing the confidence and capacity of the care staff team to better meet the needs of those in their care. It would

be necessary also to have more specific evidence in addition to this, about confidence and capacity and whether or not the care staff have grown in their ability to be more imaginative and effective, in relation to the provision of these kinds of DMP based activity. I would argue that the second questionnaire provided that.

The second questionnaire, Participants Evaluation Questionnaire (PEQ, Appendix E), was given to participants, and completed by them, on the final Review Day of the programme. There were sixteen participants on the day and thirteen questionnaires were completed and returned by hand giving a return rate of eighty-one-percent which was significantly better than the previous questionnaire. The PEQ was more sophisticated than its predecessor with fifteen different questions and again a variety of different techniques with the addition of quite a few 'tick-box' type questions. It was designed to investigate the impact on the care staff of the training programme. This had included on and off-site training with opportunities to practise their skills without my presence at the session and a review day to close. After the three initial on-site sessions with me they had been left to develop their own approaches to session provision, including planning, delivery and review for the following four weeks up to the Review Day. This was important in terms of training programme design, as it meant care-staff could try out in teams some of these new skills and ideas identifying their strengths and weaknesses as they went along and reflexively learning from experience.

Results were unequivocally in favour of the hypothesis that care staff have increased their confidence and capacity to meet the needs of those within their care more

imaginatively and more effectively. Question 8 (see appendix E) asked: ‘Has the training increased the confidence and capacity of you the staff team to meet the needs of those within your care more imaginatively?’. Twelve answered yes and one remained uncompleted. Question 9 asked: ‘Has the training increased the confidence and capacity of you the staff team to meet the needs of those within your care more effectively?’ Thirteen people responded with a ‘yes’. This was clear evidence that Aim C can be answered in the affirmative. Other answers to open questions also support this view: ‘Overall atmosphere (on the ward) has improved. Greater sense of motivation. Staff more happy and experiencing greater job satisfaction. Residents happier and more lively’; ‘ I feel it is a better atmosphere on the ward for staff and clients, making us all happier to see clients smiling more and some clients talking about it after session’ ( both responses to PEQ No.13).

## **7.6 Themes and Meta-Themes**

### **7.6.1 Themes**

In section 7.4.2 above I began to describe the process by which I arrived at the ‘Notes and Themes’ Column (Appendix A). I analysed the dialogue, basic body movements, including music and the relations between them, looking for patterns, emerging themes and phenomena that interested me as researcher/practitioner. This section aims to refer to and analyse the themes in more depth including those initially identified and referred to in Appendix A. Appendix B is a table that identifies the most significant of the themes by way of their frequency of occurrence in the transcript.

Without several cameras and sophisticated recording equipment it was not possible to capture on VTR all aspects of the session as it unfolded. The transcript is therefore an incomplete record and Giorgi has warned researchers not to be fooled into thinking one has captured everything in the VTR (Giorgi, 1994, cited in Palo-Bengtsson, 1998: 20). It is however an important attempt in real time, to capture and gain insight into human actions, communication and behaviour during the session. It was made at little expense using VTR equipment available on the high street and this data set was supplemented by the DCM data also recorded at the same time by an independent observer in the same room. Comments in blue in bold and upper case (Appendix A, time and title), aimed to link the DCM data with the film transcript so the two data sets could be correlated. After filming, two different versions of the film were given to me by the film-maker: the first was an edited and shortened version, the second an un-edited version. I chose to use the second version from which to compile the transcript since it was a more detailed and complete record. The left hand column in the text was colour coded to differentiate the three underlying phases that can be generalised to sessions of a similar type. Orange colour denoted 'Warm-up' phase, yellow denoted 'Development' and green denoted 'Closure' phase.

Methodologically, from the perspective of practitioner/researcher, my attempts to categorise phenomena in the analysis of the VTR ran the risk of bias. For example, with only one available camera I was restricted in this analysis, as it was not possible to capture the sequence where Gladys left the room and walked down a neighbouring corridor; this was very significant in the context of the session. There were other

moments when I would like to have explored Gladys's movements, around the room, in relation to Arthur's communications which were difficult to interpret. Other factors may also have had an impact including: 'selective attention': 'selective memory': 'selective encoding' and 'interpersonal factors' (Robson, 1993: 202-4). The combination of the use of VTR data, DCM scores and staff questionnaires as well as my own observations meant that the session and its impact could be investigated from a variety of perspectives. These I would argue add weight and depth to the analysis and reduce the bias of the factors referred to above.

I have in previous sections of this chapter described and discussed some of the themes that were listed at the top of the table (Appendix B). First, there was the care-staff contribution to the session (7.5), second the use and importance of 'embodied practices' including physical mobility and exercise, rhythmic movement and dancing ( 7.4.1 to 7.4.7). Other themes were also important and need further analysis in this section although it would be inappropriate to describe in detail all thirty-three. These included in order of their importance in Appendix B:

- Theme 9b 'Differing Narratives.'
- Theme 7 'Giving Praise'.
- Theme 10 'As if..'
- Theme 4a 'Importance of music'.
- Theme 6 'Maintaining Identity and Symbol Formation'.
- Theme 14 'Working with fragments'.



### **7.6.2 Theme 9b ‘Differing Narratives’**

This describes the differing or individual narratives that people with dementia appear to be following or engaged with in a session. These narratives take the form of stories, or words linked together, that appear to be unique to the individual. I would argue these narratives are not unique to a session of this type, as indicated by the fact that they seemed to continue once the session had finished. They would appear to be closely linked to, and influenced by how people make sense of their world; the process of ‘meaning-making’ becomes problematic, and breaks-up for people with dementia as the confusion grows. Widdershoven and Berghmans, (2006: 190) argued that the challenge for care-staff is to:

find ways to reintegrate these perspectives once again. This requires a dialogical attitude, exemplifying both openness and preparedness to change. A fusion of horizons is not a conscious achievement brought about through the exchange of information. It is a realignment that occurs when people take part in joint movements and rituals and find themselves changing into a community.

This is an important quote because the writers refer to a ‘dialogical attitude’ that links very well with how I have been framing the concept of ‘building bridges of understanding’ in this thesis. This process of understanding is also dialogical and seeks reintegration and realignment, not through the conscious ‘exchange of information’, but through engagement in a psychotherapeutic process where movement, ritual and meaning-making are the medium through which these processes

happen. The session is therefore, metaphorically and psychotherapeutically speaking, a 'process of intersection' (Feld and Keil, 1994: 78). It is a meeting place and a context for the dialogic, relational and inter-subjective processes to take place. The 'differing narratives' (Theme 9b), the 'raw material' of the individual stories are heard, related to and worked with in open, respectful and searching ways.

### **7.6.3 Theme 7 'Giving Praise'**

This is a way of validating persons in the group involving witnessing, recognising and valuing the verbal and non-verbal communications and behaviour they make (including staff) by verbally or non-verbally giving praise to the person. This has important links to the meta-themes (building relationships through embodied practices, maintaining identity and personhood).

### **7.6.4 Theme 10 'As if...'**

As a Dance Movement Psychotherapist I am constantly attempting to make sense of people's 'differing narratives' (Theme 9b), their wants and needs, thoughts and feelings. Central to this search is the question of how to make sense of the words, phrases, metaphors and stories etc that people are communicating. We try our best to fill in the gaps of our 'not knowing', we make sense out of 'non-sense', we make difference and diversity in our communications and relationships the norm rather than the exception. This means once again that the onus is on the psychotherapist to enter into dialogic and inter-subjective communications with patients, eliciting the intention and meaning underlying the communications. My studies have helped me

link my clinical experiences of this approach, theoretically into the work of Vaihinger, who in 1925 first described the ‘fictions’ that we create having no basis in reality but which nevertheless help us cope with our lives better (Vaihinger, 1925 cited in Snyder, 2006). Ansbacher and Ansbacher (Ansbacher and Ansbacher, 1956 cited in Snyder, 2006) later took this further, coining the term ‘as if’, describing these ‘fictions’ as subjective constructs we live by, regardless of any objective reality. Snyder recently has added, ‘ if we listen to people with dementia ‘as if’ what they say has meaning despite their communication difficulties, the outcome of conversations may be quite different and the fiction may begin to change’ (Snyder, 2006: 264). This theme in the context of the session analysis is important as there were eighteen occasions when I identified this taking place. This could also form the basis of a technique or way of enabling care staff and carers to pay closer attention to the meaning underlying the words, when the words themselves apparently make little sense.

#### **7.6.5 Theme 4a ‘Importance of music’**

The use of a mixture of live and recorded music in a session with people with dementia is very important in this context. The appreciation and use of music appears to act as an important medium of communication, a way of tapping into past life experiences, supporting self-esteem and reducing depression. Significantly, two pioneering music therapists working in the United States, Hatfield and McClune, have identified and reported an important shift of emphasis, away from music therapy as behavioural intervention to psychosocial support. ‘More and more we see the focus

shifting from music therapy as a behavioral intervention to music therapy as a means of comfort, growth and continued well-being for the person with dementia in an overall program of person-centred care' (Hatfield and McClune, 2001: 84). This is paralleled by my own sense that in Dance Movement Psychotherapy with this population it is more realistic and appropriate to think in terms of the psychotherapy supporting *palliative* approaches to treatment and care, rather than treatment or cure which would be more achievable with other populations. Music also has important links to singing and other themes including Theme 4a rhythmic movement, and the over-arching meta-themes of: building relationships through embodied practices; supporting emotional communications; staff training and development; providing enjoyment and supporting well-being.

#### **7.6.6 Theme 6 'Maintaining Identity and Symbol Formation'**

This theme is an acknowledgement that for people with dementia suffering many losses in relation to activities of everyday living and neurological functioning including memory, questions around 'identity' and place in society and the world, are of increasing importance. Often, in clinical practice, these important existential questions are present either consciously and/or unconsciously in everyday communications and behaviour. People often may need reminding of who they are. The following exchange took place between LC and Gladys and was captured by the VTR. LC asks Gladys (calling her by a nick-name Rose) whether or not she is alright; 'Yes', says Gladys, 'I'm just looking to you to let me know where I am'. This aside, which I picked up only on analysis of the VTR, revealed that staff can help patients

maintain their identity, if they are aware or can recognise that ‘identity’ is an important matter for the person. Taken simply, this comment can be interpreted as the person needing to know where they are in space, in a room or whatever. A day-attender in a Day Centre with whom I have been working, keeps annoying others by saying to them repeatedly, ‘I’m Sarah Jane Loxley’ as if to be reminded and to remind others that this fact is true. Taken literally it is obvious it is her name. However, there can often be a deeper psychological need or existential meaning underpinning these seemingly simplistic communications relating to self-identity (who am I?). Bowlby’s pioneering work on theories of early Attachment (Bowlby, 1969) in children and their parents, are relevant here and describe the importance of a sense of belonging and knowing one’s place in the world in relation to early parental attachments made. I consider there is evidence here that these needs re-occur when that world may be falling apart. For example, sometimes it is enough to reply by saying the person’s name; however if this gets repeated and repeated, as often happens in clinical practice, the questioning and searching is then more likely to be about *identity* rather than ‘name’ per se. Psychologically, this compares with what Nyström and Lauritzen (2005) have referred to as the existential themes that were present in their research and that underpinned much of their Dance Therapy work, ‘issues of ageing, loneliness and loss of dear ones as well as bodily capacity: how long can you live, how old do you feel, the possibility to feel young at heart despite an old body and to accept your destiny’ (Nyström and Lauritzen, 2005: 313). The patient’s need for re-assurance that they exist, that they belong in their community (attachment), that they are valuable to those in their immediate vicinity including family and loved ones; these link back to the ‘webs of interlocution’ (McMillan,

2006: 67), the networks of interpersonal relations that surround us and enable us to grow and maintain a sense of self in the world. These are fundamentally intersubjective and important processes that I have discussed previously in section 7.4.7 in relation to Arthur.

The importance of symbol formation in the Dance Movement Psychotherapy context refers to the special circumstances created by the mixture of the expressive modes of rhythmic movement, music, dance, song and interpersonal relations between patient, psychotherapist and staff. These expressive modes, in combination, allow feelings, emotions and memories to constellate and surface from the unconscious. For example, at 10.45am I started rocking side to side with Gladys in time with the music and we made strong eye contact; I also sang the words of the song to her. This pattern was repeated during the session at different times (10.50 and 11.00 and 11.05am) in slightly different ways and also with MM (11.20am). The effect was that in combination, these experiences had an important emotional charge for her and at several points she tried to kiss both MM and me on the cheek, which was also an emotional expression and identified in the themes section (Theme 12). Symbolically, I think the session was constellating a need on Gladys's part for emotional depth and physical even sexual expression, as previously reported in the DCM scores for one five minute time frame (Chart 2). The session was able to meet Gladys's individual needs within the therapeutic space and the symbolic way in which she expressed them.

### **7.6.7 Theme 14 ‘Working with fragments’**

Often as psychotherapist/facilitator we find ourselves working with or reflecting on a fragment of a word, a feeling, a memory, a song, a dance or story in order to help give back to the person something that is of importance to them at that moment. These can be incomplete and can involve attempts to psychologically ‘hold’ or ‘contain’ the space for an individual or group in order that something important and therapeutic can happen. These fragments are an everyday occurrence in clinical practice and often they provide important clues to the patient’s state of mind. For instance, in the 11.10am time frame Martin says the word ‘Johnson’ when he is in fact trying to remember the name ‘Al Jolson’. Once I recognise the importance of these words and their meaning, it becomes possible to play the music of Al Jolson for Martin and for him to dance with GB. This was important for him at the time. There are important links to Theme 10 previously discussed above and also to the meta-themes below of: building bridges of understanding, making sense of the fragments; maintaining identity and personhood; supporting emotional communications. Also with fragments there is the question about what we might want to be able to do with them, reflecting on their importance. Metaphorically speaking we might want, for example, to create a ‘mosaic’ with them, meaning that after we have been given a number of them they may reach a critical mass, at which point their meaning may coalesce and make sense, their importance revealed. The importance of this theme is how therapist and care-staff need to be ‘creatively alert’ (Coaten and Warren, 2008) to these fragments, as an essential part of both the Dance Movement Psychotherapy session and within the context of everyday care practice.

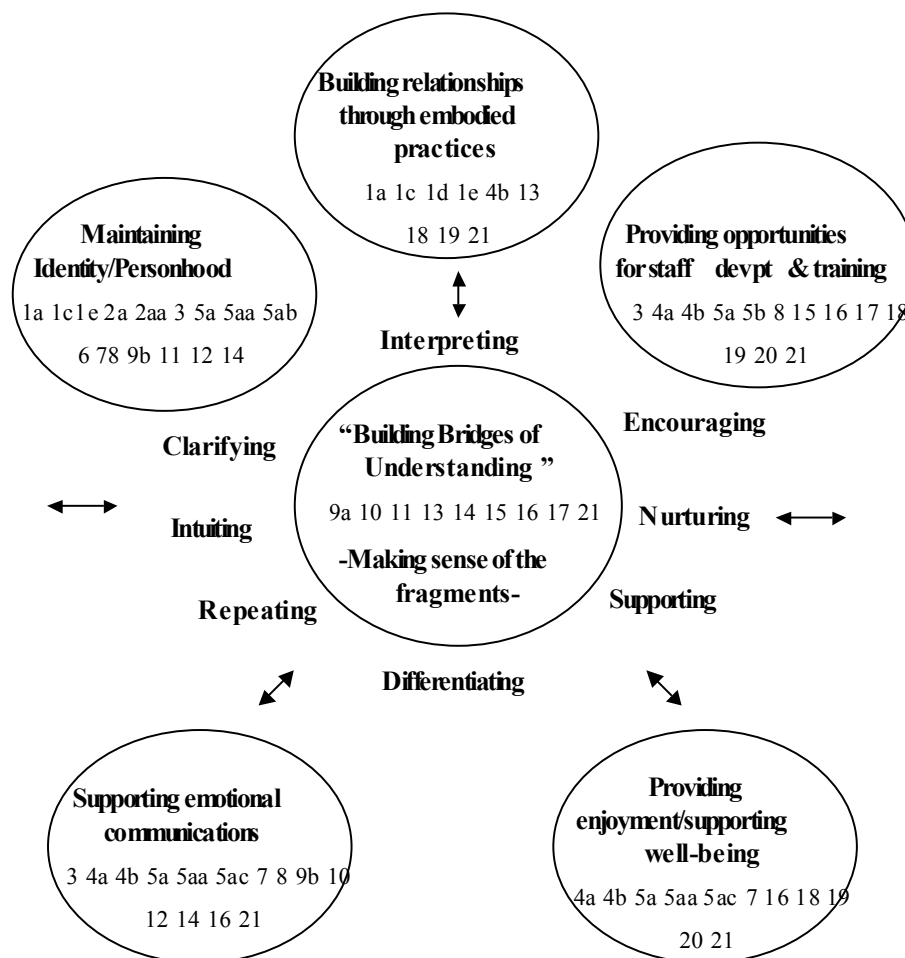
### **7.6.8 Meta-Themes**

In this section I have attempted to generalise applicability and relevance of the session to a wider audience, by identifying how the thirty-three themes identified in Appendix B link into what I'm calling 'Meta Themes' that are arguably over-arching and beyond those already referred to (see Venn Diagram 2 below). This enables links to be made between the 'Meta-Themes' and current clinical practice that I am involved with, in relation to the provision of 'person-centred' approaches to care. For example, I have a current clinical practice remit to provide staff development and training; I am also working currently with embodied practices and as a result of the studies presented in this thesis am improving the quality of psychological therapy (DMP) in the three sites where I work. Also a strategic review of NHS Research and Development funding by the Department of Health, considered as a priority, research on ageing and the diseases associated with it. One specific priority was to support research on how to 'enhance the well-being of older people and their carers and promote understanding of the needs of older people from black and minority ethnic communities' (Dept.of Health, 2001a: 142). The Meta-Themes have also contributed to 'building bridges of understanding' between different yet complementary data sets and their impact on supporting, encouraging and improving communications and relationships between people with dementia and those who care for them.



Diagram 2

## Meta-Themes



In Diagram 2, five identified meta-themes have been placed around a central meta-theme which I have called ‘Building Bridges of Understanding – making sense of the fragments’. The eight present participles en-circling the central theme refer to the ways the five other themes could be linked to the central one and vice-versa. There

could be many more present participles and processes linked in here, however I would argue these eight have emerged in a phenomenological way, out of the analysis of the thirty-three differentiated themes and so have become particularly important. The theme numbers inside each circle refer back to Appendix B and so have a direct link to the original transcript (Appendix A) and its analysis. Diagram 2 illustrates that overall meta-themes have been identified in order to broaden and deepen the data analysis and discussion of the impact of the session on people with dementia and their care-staff. The five key meta-themes have been identified in no specific order as:

- 1) Building relationships through embodied practices.
- 2) Providing opportunities for staff development and training.
- 3) Providing enjoyment and supporting well-being.
- 4) Supporting emotional communications.
- 5) Maintaining identity and personhood.

Essentially, these five meta-themes cover the main elements in this work and approach which all have to be in place and working well in the organisation, subjectively, objectively and inter-subjectively. These meta-themes are important because they lay the foundations for my proposal for the development of an approach to dementia care which I am calling ‘Creative Care’ and which will be developed and expanded in the next chapter of this thesis ( Chapter 8).

## **7.7 Reflections on the fieldwork**

I have attempted in this analysis to present a relational and developmental approach to the tasks identified, attempting to be not too diagnostic, reductionist or curative, whilst remaining curious about the complexities, surprises and discoveries referred to here. I have also attempted through this analysis to better understand individual and group based communications, particularly in relation to embodied, creative and therapeutic approaches to working with people with dementia and their care staff through the medium of DMP. I have acknowledged the complexities inherent in this process and recognised that there were potentially many different ways to view and interpret an interaction or sequence of events. I have attempted to categorise identified events and moments, especially embodied communications taking place in the session by way of themes and meta-themes; also to make links between them, differentiating one from the other, in order to better understand the processes taking place and their potential significance.

### **7.7.1 Effects on observed well/ill-being of people with dementia participating in a DMP session**

A number of different data sets were used concerning the effects of observed well/ill-being on participating people with dementia in the session. These included DCM scores, VTR analysis, staff questionnaires and my own 'scratchnotes'. Of particular interest was that each person responded differently, making the results diverse, rich and rewarding, especially when drawing conclusions about the impact of DMP on

them and linking to the work of Nyström and Lauritzen (2005). DCM analysis, for example, has clearly indicated in a quantitative and qualitative way that DMP was found to support and significantly increase observed 'well-being' for the group, for the duration of the session and for a significant period of time afterwards. By implication this also was evidence for a reduction in observed 'ill-being'. It was also evident from analysis of the percentages of time spent by individuals in the different BCCs that their range increased during the session; suggesting that it expanded the range and type of activity that participants were engaged in. This too was significant. It is also possible to conclude that this session by way of increasing range and type of activity, as well as observed 'well-being', also contributed to facilitating rehabilitation for the patient within the context of Person-Centred Care (Kitwood and Bredin, 1992c).

These findings are generalisable not only to DMP groups of a similar type in other care and NHS ward settings with this population but also to care-staff trained and supported to provide activity-based ones (see Creative Care, Section 8.3). The combination of the use of four different methodologies (DCM, VTR and transcript, Questionnaire and 'Scratchnote') has enabled in-depth perspectives on the effects of DMP on the group and the individual that is of importance to the development of the DMP profession, development of activity provision and future research in the field.

Combined analysis of the different data sets has clearly shown patients responding in ways that are unique to them, their situation, temperament, personality and condition. There were also other factors related to the environment, the situation, the context

and content of the session that taken all together, added to the complexity of analysing these different elements. What emerged in conclusion was that patients needed a response from the psychotherapist/facilitator and accompanying staff that was tailored to their own unique needs and their sense of what was meaningful for them within the group context. Gladys for example needed support in her 'Kum and Go' activity, constantly on the move, constantly open to opportunities to meet someone or something that she could engage with. It was meaningful and important to her that the session and its facilitation was able to allow her to continue this behaviour and the psychological need underlying it, which I interpreted as the need to maintain relationships with people and things (e.g. session props). Arthur did not value the group context as much, indicating via the DCM scores and the VTR analysis that one-to-one working would perhaps have been more beneficial for him. However the spiritual context that emerged leading him into spontaneously singing a hymn was very meaningful for him and very difficult to predict. The meaningful nature of these engagements and relationships also linked to the importance of emotional expression (Ward et. al. 2005, 2006a, 2006b, Sheard, 2008a and Kitwood, 1997a). There are also links to the importance of and need for meaningful activities generally in dementia care (Crichton, 1997, Harmer and Orrell, 2008, Perrin, 1998, Perrin 2005, Perrin and May, 2000).

When Gladys received the attention she needed by way of meeting someone who responded well to her, coupled with the opportunities to handle and relate to props, her observed 'well-being' increased. This response to the session I interpreted as similar to Arthur, that she might need more one-to-one contact outside of the session.

There is also the implication, by way of these responses, that sessions of this type do not take place in a vacuum but are inextricably essential to what happens before and after them.

The richness of the results and responses from patients was also evidence that the Dance Movement Psychotherapist must be open to the unexpected, to the not-yet-known; and to all that I have argued previously in this thesis about the importance of treating the perceived 'difference', the 'strangeness' and 'otherness' as the norm rather than the exception. There is evidence also from Gladys that the therapist needs to be open to the 'quick-witted' verbal riposte that surprises psychotherapist and facilitator alike. The response gives the lie to assertions that even with severe dementia individuals no longer have access to their previous skills, abilities and memories whether verbal and/or non-verbal.

There is strong evidence too from the data analyses in the context of attempting to normalise dementia, for the importance of the Dance Movement Psychotherapist being able to identify and focus on what it is still possible for the person to do, say and remain in relationship to, within the context of communication and meaningful activity. In addition to increases in well-being thereby reducing stress and anxiety, there are for the care-staff witnessing these occurrences, opportunities to reduce the stigma associated with them.

### **7.7.2 Identifying embodied practices occurring during the session and their impact on both people with dementia and their care staff**

The main focus in the data analysis has been on the widest possible attention paid to what embodied practices are and what they mean, in the context of the session involving work with people with cognitive deficit including memory problems. Implicit in the conclusions drawn here, are that embodied practices and ways of relating to the lived experience of people with dementia through their bodies, matter a great deal for them in line with other studies in this area (Coaten, 2001, 2002, Crichton, 1997, Donald and Hall, 1998, Gibson, 2002, Gräsel et al., 2003, Haisma, 2008, Hatfield and McClune, 2001, Hill, 1999, Kindell and Amans, 2003, Kontos, 2004, Meddaugh, 1998, Nyström and Lauritzen, 2005, Palo-Bengtsson, 1998, 2000, Perrin, 1998, Phinney and Chesla, 2003, Shustik and Thompson, 2001, Zachow, 1984).

It is necessary here to make a distinction between two types of embodied practice in order to acknowledge their differences. In reality it is a somewhat arbitrary distinction, because the conclusions drawn from both are equally significant yet each distinction relates to a different context and that matters to how significance can be interpreted.

The first type concerns the explicit attention paid to the impact and analysis of embodied movement and dance practices as provided by the DMP session on participants including care-staff. The second concerns the implicit attention needed and paid by care-staff towards care practices that are embodied but not necessarily

related to DMP in the context of a session. The reason for this distinction widens the influence of embodied practices in dementia care generally, and helps allay potential criticism that embodied practices only relate to DMP as discussed in this thesis. In reality they exist in all care practices involving relationships, movement, communications and behaviour. This distinction helps delineate one from the other providing relevant examples in both areas.

The concept of ‘Creative Care’ discussed in Chapter 8 (see section 8.3), aims to build on the implications of these embodied practices for ways to improve training and development of care-staff in embodied practices and to begin to develop their use in the field in relation to improving communication and relationship.

### **7.7.3 The impact of embodied practices on people with dementia as experienced through the DMP session**

The three most significant embodied practices identified in the fieldwork are: ‘physical mobility and exercise’, ‘rhythmic movement’ and ‘the use of dancing’. They represent good evidence for the importance of embodied practices used in the DMP session. There is a strong case here for arguing that important links exist between the frequency of occurrence of embodied practices as evidenced by DMP, and an increase in ‘well-being’ as evidenced by the accompanying DCM analysis. It is realistic and logical to deduce that DMP has helped support and contribute to a significant increase in observed ‘well-being’ for patients both during and post session.



I have previously outlined in Chapter 3 the idea of ‘revealing the hidden humanity within dementia through movement, dance and the imagination’ (Coaten, 2002: 386), where I describe the importance of ‘embodied practices’ in the context of a session very similar to the one studied in this thesis. This means that:

...we enter into a realm where people can be given back something of themselves that they may feel they have lost, sometimes without even being aware that they may have lost something. It is not me or the worker or carer that does this, although these relationships are central to the process; rather it is the way in which the arts allow expression of that for which there is no other way (op.cit.: 391)

The process I describe here is one of a giving back to the person of something ‘lost’ or ‘forgotten’, and in the context of this thesis, further developed here into one of the central ideas behind the construction and development of what I am calling ‘Creative Care’ based on embodied existential knowing. As a creative and embodied approach to the person living with dementia, the session opens up different threads and pathways to facilitate relationship with and between people, by engaging them in a variety of imaginative, enjoyable, spontaneous, musical, rhythmic, emotional and creative responses to material presented in a session. Patients’ responses once recognised by care-staff and other professionals, including any noted individual changes and significance for the person, can be fed-back into their on-going care planning and treatment programme. A programme of sessions contributes, as previously argued, to revealing remaining and sometimes hidden potentials and

abilities that arise through the embodied practices; practices that include singing, moving and dancing, music, remembering, telling stories, the use of props, all of which are also important to supporting 'Personhood' (Kitwood and Bredin, 1992a: 274).

During sessions meaningfulness is built through relationship, that according to a recent study, is centred on values and beliefs linked to the person with dementia's past 'roles, interests and routines' (Harmer and Orrell, 2008: 552). Also according to the study the characteristics of the experience were important: 'activities that addressed their psychological and social needs, which related to the quality of the experience of an activity rather than specific types of activities' (op.cit.: 548). This links well to the findings of the Perrin study of the Jabadao session (Crichton, 1997), that the personality of the facilitator was perhaps more important than the activity itself (Perrin, 1998). We have evidence here for the importance of communication and relationships between psychotherapist and patient influencing outcomes in a positive way and also for the way in which the session was carried out relating to the quality of the experience itself, rather than the specific activity type.

The link between these studies and DMP is that the activity itself may not matter as much as *how* it is carried out, the *quality* of the ensuing experience and the *relationships and communication* developed between all concerned, facilitating a sense of individual meaningfulness. The response of the individual to DMP and the embodied material presented, is of great importance together with a 'sense of enjoyment', which the study above also reported (op.cit.: 552). A sense of individual

meaningfulness triggered in response to the material, matters a great deal in the context of a giving back of lost verbal or embodied abilities and memories. Thus the revealing of a hidden or lost humanity within the condition through these embodied practices of music and dance, contributes to ameliorating the many losses experienced by the person with dementia and according to Norberg, (2001, cited in Gotell, Brown and Ekman: 412) enabling care-staff to maintain a focus on 'possibilities rather than on limitations'.

There were other significations in relation to embodied practices in the session related to the frequency of occurrence of 'working with fragments' (see section 7.6.7). It is important for care-staff to be able to hear, recognise and work with the fragments of thought, memory, word, movement and behaviour that occur in a session. Table 6 indicated thirteen occurrences that fitted this description. They are valuable indicators of a patient's response to the session and its contents and these are generalisable to sessions of a similar type. They also link to relationships with others and to the sometimes difficult and frustrating process they go through to re-member the lost words, memories or whatever it is they are searching to find. If we are able during the session to help patients relate to and connect with these 'fragments', then again we help facilitate the process whereby they can be helped to 'build bridges of understanding' between these lost 'threads' or fragments of themselves. The stressful nature of forgetting can also be ameliorated in relation to care-staff and psychotherapist, working better with these fragments in order that metaphorically speaking, a re-affirmation of structure and identity emerges and a 'mosaic' can be created. A 'mosaic' is what is created out of the juxtaposition of fragments and may

be a contributing factor to an increase in observed 'well-being'. At some level the person experiences a feeling of connection and relatedness again, in spite of great loss and dysfunction at other times.

Singing (McMorland, 1998, Got  ll, Brown and Ekman, 2003) was another important embodied practice for the patient and also for the care-staff during the session, tapping-in as it does to past memories of singing at home around the piano, or as a child at school and supporting observed well-being. Interestingly, there is a phenomenon which I have experienced a great deal in my clinical practice that patients may have profound word-finding difficulties, yet on being asked to sing can remember many of the words of a song.

Table 6 also referred to the use of props as being significant in supporting embodied practices. Props included the use of stretchy elastic or 'pink elasticated band' (see Appendix A, 10.40am), for bringing a sense of connectedness to the group. This enabled people with cognitive deficits to hold on and sense through their bodies how the elastic is moving and how they might, through holding-on, resonate with the sensation of that experience and find it a pleasurable experience. For patients able to actively initiate movements through this activity rather than passively, it can provide a sense of satisfaction and support for their 'personhood' (Kitwood and Bredin, 1992a: 274). Ribbon-sticks and scarves are also used for enabling embodied practices through related body and arm movements supporting creative expression and heightened sensory awareness through the movement and dance activity.

#### **7.7.4 Embodied practices and care-staff generally**

Staff developing a greater awareness and importance of the ‘lived’ and embodied experience of dementia can make a significant positive difference to people’s lives (Bruce, 2002). Kontos (2004) describes in her study the importance of the concept of ‘selfhood’ as a fundamentally embodied dimension, which she argues as ‘characterised by an observable coherence and capacity for improvisation and sustained at a pre-reflective level by the primordial and socio-cultural significance of the body’ (op.cit.: 829). This ‘coherence’ and ‘capacity for improvisation’ she argues continues into late-stage dementia and links well with Radden’s concept of a ‘Co-ordination unity’ referred to previously. These arguments are very significant in the context of embodied practices, for if both Kontos and Radden are correct, care-staff can proceed by way of better understanding how this ‘coherence’ translates into everyday actions and behaviour for the person; evidencing the need for training to address the opportunities presented. Also if the older person still retains a ‘capacity for improvisation’, how might care-staff be able to respond coherently and react *improvisationally* in response to this remaining capacity? Again, bridges need to be built between these theoretical insights and their practical application with care-staff who will need to understand them not so much in cognitive, rather in embodied and experiential ways, using language and concepts that are as far as possible jargon-free and meaningful to them. Care-staff need to be given opportunities to palpate this improvisational aspect of care first for themselves, witnessing and experiencing it in practice, then to be able to explore and develop its application with those for whom they care (see Chapter 8 section 8.3).

I argue here that embodied practices make an important contribution to the nature of how care-staff carry out their duties, to the quality of care relationships enhanced by improved awareness and understanding of them and better support for ‘personhood’ (Kitwood and Bredin, 1992a: 274). Care-staff can be enabled to pay more attention to the lived and embodied experience of how and why people move as they do, and in cases where they are not sure, to have insight into the factors influencing the person’s movement behaviours and preferences; in other words to ‘build bridges’ between what they can and cannot immediately make sense of. Care-staff can learn, for example, that attention to non-verbal embodied practices, such as how you hold someone walking down a corridor while toileting, can make a big difference to how the person with dementia experiences themselves and that member of staff in the process. It can either hinder or support observed ‘well-being’ for the person with dementia and make a great difference to the quality or otherwise of the care relationship with that person. This process is additional to and supportive of current health and safety practices in relation to ‘Moving and Handling’ guidance. Care-staff can also be helped through the use of embodied practices to become aware of vitally important areas in care practise, such as how to calm a person down who may be very upset, or who may indeed be screaming. For example, ‘Music-therapeutic Caregiving’ (MTC) (Brown et al., 2001) including musical activities and caregiver singing has been found to have profound effects illuminating the movement and sensory awareness aspects of people with dementia during care routines. Results indicated for example that subjects in the study gained ‘straight, balanced bodies’ with ‘alert senses’ (Got  ll, Brown and Ekman, 2003: 419). Caregiver singing means

singing to the person with dementia while carrying out everyday care tasks and by so doing it enriches the quality of the care experience:

Perhaps the most profound change, though, was that related to the communication between caregiver and patients. Patients seemed to have an implicit understanding of what caregivers were communicating, and this clearly transcended the use of verbal instruction, as the caregivers were singing about folk themes, such as love and nature, and not about the caring activities at hand (Got  ll, Brown and Ekman, 2003: 427)

Of particular interest here is the way in which the creative approach, in this case singing, takes the focus off the care tasks themselves and onto the *quality* of the care experience, as discussed earlier, touching here on universal themes of love and nature (Harmer and Orrell, 2008). This is another example of the essence of the communication being ‘dialectical’ and the meaningful part, taking place in the ‘process of intersection’ (Feld and Keil, 1994: 78). Care-staff can be helped by way of the singing to build bridges of understanding between the everyday and potentially mundane care-task and the emotionally congruent, coherent and improvisational nature of song and singing. This becomes therefore an experience that is uniquely tailored to the person by virtue of the choice and relevance of the particular song and the relational aspect of care-staff able to pick and sing the most appropriate one. The researchers recommended in an earlier paper that in response to the outcomes of their researches, caregivers/care-staff should have some basic training in singing in order

to best carry out this approach (Brown et al., 2001). I would incorporate this idea in the content of what is described below as ‘Creative Care’ (see section 8.5) that could be incorporated into the training of care-staff as a valid arts practise.

Other conclusions drawn are that care-staff can improve their embodied care practices by learning to become more proficient in recognising the use and importance of sensory pathways in their work. These pathways include work in the following channels of sensory communication, auditory pathways (hence the link to the importance of singing as described above), visual, olfactory, body language and tactile stimulation (dance and movement work can help here), including development of the kinaesthetic sense.

### **7.7.5 Reflections on the Care Staff**

Specifically, in relation to the Care Staff, the session and the accompanying training programme have highlighted that this work and approach is not just about raising the quality, or ‘doing’ better care, it is about being more in relationship with others and having a more *rewarding experience* as a result, as evidenced by the staff comments in the questionnaires. It will feel risky, very risky, to develop our communications; however, I would argue we have no choice but to do our utmost to find those ‘best possible routes’ to enabling communication (Ward, 2002b: 36) for the care-staff as well as the person with dementia. The meaning in this work and in this analysis, lies practically, metaphorically and symbolically by way of building those ‘Bridges of Understanding’, not so much about what happens on each side of the bridge, but about what takes place in the middle; the place where the ‘known’ and the ‘not-



known' meet and the resulting intensity or not of that interaction.

It was very significant that the 'importance of staff contribution to the session' (see Appendix B Theme 5b) received the most number of occurrences and therefore topped the list of themes identified. Given the high ratio of staff to patients (six to four) in the session, this is perhaps to be expected, but there was a strong training element to it that indicated staff as fully involved and participating well. I have also argued previously (see section 7.5) that care-staff helped contribute to raising observed well-being, facilitating participation and social interaction and from my own observations that they demonstrated a growth in confidence, capacity and understanding of what to do and what not to do in relation to support for the session.

Analysis of the OEQ and PEQ questionnaires indicated significant benefits for the staff under five different headings. **'Caring more about the patient'** indicated an identified and acknowledged need to spend more time with them as distinct from time spent in a task-oriented way. This was connected to a positive attitudinal change to the provision of activities and is a telling indicator of the session's impact on the care-staff generally. This is consistent with previous research that attitudes can change as a result, from 'dreading' the care of people with dementia, to one of 'excitement and creativity' (Schwab et al. 1985: 14). I would argue that this staff development aspect is also generalisable, together with a reasonable staff expectation to see potential new behaviours and/or communications in patient responses and contributions where session structure, content and themes remain relatively similar to this session. This factor is also important in terms of the opportunity it provides for giving care-staff

insights into how best to be able to develop their communications in this field. As eloquently argued by Morris (1999): ‘(u)nderstanding and responding to communication problems and behavioural difficulty are arguably the two most challenging and stressful aspects of caring for someone with dementia’ (op.cit.: 28). This argument was reinforced in researches by Ward et. al. (2005), highlighting that in everyday care-work, for care-staff: ‘...the format of directives and narration of tasks, which we called ‘care-speak’, put clear constraints on any opportunity for residents to have input to episodes of care’ (op.cit.: 18). Communication other than to do with ‘task-oriented’ approaches is a serious problem generally and has been reported widely in the literature (Goldsmith, 1996, Kitwood 1997a, Killick and Allan, 2001, Morris, 1999, Perrin, 2005). Any activities including DMP that improve communications between people with dementia and their care-staff in the context of developing relationships are therefore of great significance in the context of dementia care.

The DMP session also provided an experience that gave participating care-staff an **‘Emotional Impact’** giving more emotionally congruent information, awareness and knowledge about the person with dementia than might otherwise be the case in everyday care practice. This is based on the assumption that emotional ‘bridges of understanding’ have been built between all involved and the quality of the experience has been particularly memorable as a result. Emotional impact on the care-staff is of particular contemporary relevance as it helps build relationships, supporting ‘Personhood’ (Kitwood and Bredin, 1992a: 274) and in the context of the ‘Senses Framework’ (Nolan, 1997, cited in Nolan et al., 2008) contributes to support for all

five senses of ‘Security, Belonging, Continuity, Purpose, Achievement and Significance’ (op.cit.: 27).

I also identified here that care staff in response to this DMP session and its impact on them, have been ‘*gaining new ideas*’ about the use of props (scarves/ribbons on sticks) and music in relation to provision of sessions of this type. These ideas were new to them and they were able to witness their impact on patients during the session and how much they were able to support engagement, enjoyment, social interaction and embodied practices. This is relevant in terms of future attempts by the staff to run sessions of a similar type by themselves and is another generalisable aspect to other sessions of this type. Staff should therefore be better able to understand and use these materials in future sessions of their own making.

‘**Future benefit**’ was another outcome of the questionnaires that indicated staff identified a sense that their participation in the session and the training programme would be of benefit to them in the future. This clearly represents a positive outcome for them in the sense that they are able to project forward the value and importance of the session and its impact to ones of a similar type and indicates the value they attributed to it. It does not imply that they will actually *do* it, which is in part why I think they also reported the ‘*need for improved session planning, preparation and debriefing*’. I argue that the development of ‘Creative Care’ is a necessary structural, contextual and practical framework to enable care-staff to carry it out and the work to grow in response to these affirmations of importance and value from care-staff.

Finally the session and the training generally, provided the opportunity for care-staff to learn some key factors in the provision of activities, what Perrin (2005) has described as essential in effective activity provision:

- an unshakeable belief in the potential of activity to improve a person's health and well-being.
- an understanding of the links between activity and health and inactivity and ill-health.
- evidence of the capacity of activity to generate positive changes in a person's health and well-being (op.cit.: 27).

These statements from a very experienced Occupational Therapist in the field also have relevance for the care-staff in later sections of this final chapter, with regard to Perrin's call for 'an unshakeable belief' in the potential of 'activity' to 'improve health and well-being'. All three reflect an acute awareness on Perrin's part of the importance of the values and beliefs held by those providing in this instance activity-based sessions or in my case DMP. These statements also make good foundations on which to build on necessary staff development and training in this area currently being actioned in relation to the development of a National Dementia Strategy (Dept. of Health, 2009).

#### **7.7.6 Personal Surprises**

Overall, there have been several important surprises. One has been for me to discover the processes to be more diverse, more complex and embodied than I first thought

and it has given me a much greater awareness of and respect for that which may be taking place under the surface, or on the margins of perception (see below). This has meant in relation to my current clinical practice, a need to be more sensitive and aware of the behaviours and communications taking place that are particularly subtle. Second, the VTR analysis has revealed that processes, communications and behaviours were taking place about which I was unaware at the time. As a result of the repeated viewings as researcher/practitioner it was evident that I missed a lot while my focus was on some other ‘happening’ in the space. To see it recorded in front of my eyes via the VTR and to be able to keep playing it, over and over again, was a salutary reminder of the degrees of complexity and how much I missed. Arguably, important aspects of the session were missed in real time by me that could have been taking place in my own psychological ‘blind spot’, and there may have been good psychological reasons why I was not able to spot communications or behaviours which may have touched a difficult or emotionally vulnerable place for me. For example, I was not aware of the degree to which Gladys and Arthur’s communications were so intertwined, involving what I have described as the ‘complementary narrative’, where each influenced the other, although in these examples there was often a delay just to complicate analysis even further. Also during the 11.00am time-frame I found myself resisting Gladys’s attempts to kiss me on the cheek, in response to the dancing we did together while holding hands. This was an emotional moment for both of us. Gladys responded naturally and emotionally, whereas I was more aware of the need for professional boundaries and therapeutic distance and responded less openly and naturally. Psychologically and professionally it was a challenging moment for me.

There was also a professional need during sessions to look out for and pay attention especially to what was happening at the margins, at the edges of my perception. To work hard, for example, to get under the surface of what at first glance might seem as ‘non-sense’, or incongruent, or to what others have referred to as ‘often vague, fragmented or in different ways ‘uncompleted’ contributions to communication’ (Nyström and Lauritzen 2005: 302). These often reported and described moments of vague, fragmented, uncompleted and baffling communications and behaviour are the norm in dementia care. However, according to some we are charged not to accept this myth. I would justify this by referring to the work of contemporary researchers in communications with people with dementia: ‘It is as though we always expect them to make the effort to communicate and demonstrate improvements *for us* but rarely do we attempt to make the effort to communicate *with them*’ (Vass et al., 2003: 29). This is an important point and I would continue, that if we had the ‘ears’ and the sensory perceptive systems tuned to hear, see and accept these different/diverse forms of communication as the ‘norm’ rather than the exception, dementia care could be transformed. This essentially means acceptance of the intention to communicate wherever, whenever and however it arises by the person with dementia, however baffling, disturbing, or emotionally challenging, placing the burden of interpretation, understanding and effective meaningful response firmly on the shoulders of others. Goldsmith an acknowledged pioneer in the field echoes this responsibility powerfully:

It is the argument of this book that great numbers of people with dementia, even in advanced states, who are not thought able to communicate, actually have a great desire to do so. It is for others to acquire the skills which will enable them to understand and interpret the experiences and views of those who struggle to make themselves heard (Goldsmith, 1998: 14/15).

This exhortation by Goldsmith and others (Vass et al, 2003, Gibson, 1999) remains far easier said than done. Many care-staff lack the information, knowledge, skills and experience to be able to do this and this will remain for the foreseeable future one of the most significant challenges for the dementia care field; to improving the quality, depth and range of care staff's communications with people living with dementia.

#### **7.7.7 Importance of Clinical Supervision or its equivalent for care-staff**

Clinical supervision for the Dance Movement Psychotherapist is a vital process and embedded in our Code of Professional Practice. It is designed to help develop awareness of the subtleties of communication that take place in our clinical practice. Occurrences and communications during the fieldwork phase and referred to in the section above, that are personally surprising, take on a different meaning from the perspective of clinical supervision; these are to be expected when put in the context that not everything taking place is possible to capture in a session. The role of the clinical supervisor is to help identify for the therapist/practitioner the extent to which they are fully aware of events and happenings taking place, especially those aspects of the session and relationships between people that give rise to 'blind-spots' as previously described above. It is likely that in every session there will be aspects of it

that are difficult to remember, to relate to or emotionally connect with, because of our own psychological make-up. There is no blame to be attached to anything or anyone; from a psychotherapeutic perspective this is a natural phenomenon inherent in all communications and relationships. Clinical supervision helps the therapist become aware, through a witnessing and reflexive process, that which they may have chosen unconsciously not to be aware of, and therefore *may* 'project', in the psychological sense onto others for any number of valid reasons. Clinical/care work with the most vulnerable and frail in our society is therefore fraught with relational and communication difficulties of this type. I like for example, Guggenbühl-Craig's (1999) well argued case that social-workers, care-staff, psychotherapists and all those charged with the care of others do so because at a deep inner-level they need taking care of themselves. He argues that it is: 'a special breed of person who chooses as his life's work the daily confrontation with some of humanity's most fundamental polarities (*including*) mental health' (p.15). This is because we have to be very careful not to project our own 'shadow' material and our own psychologically based needs for being taken care of ourselves, onto those with whom we work (op.cit.: 1999). For this to be happening to the most vulnerable and frail in society would mean a serious infringement of their rights and yet it happens on a daily basis by care-staff who may deny the older person the right to self-respect and choice however cognitively impaired *and* however stressed the care-staff. I mean here that the care-staff, for example, risk making decisions for the person without consulting beforehand whether they have the consent or not of the person for that action (involving any number of care tasks) and doing so on the basis that *they* know best; or that they *assume* that they know best. This psychologically charged aspect of the



process of care may contribute to why, according to Ward et al. (2006b: 24) the experience of residential care involves: 'prolonged and unremitting social isolation' because the quality of communications and relationships desperately needs improving and proper staff supervision, training and support is essential to it.

I was fortunate enough to have had clinical supervision on a regular basis. However for care staff there is no such thing as clinical supervision, or any recognition that running sessions of this type is demanding emotionally, physically and psychologically. This raises an important question concerning how staff can be better supported in this task. To whom can they turn for support, for reflexive practice and supervision, not just in running sessions of this type but in their care-work generally? All of us working in this field need much more awareness about that which at first is 'not known' and incongruent about an individual or a group, accepting that with greater awareness of embodied practices more can be achieved in care work. As a Jungian analyst once said in relation to this work, 'not to know but through search to find a way' (Shorter, B, personal communication). I find this comment both insightful and inspiring and with an on-going relevance to my clinical practice as it implies that 'not knowing' will to a large extent always be a part of the care relationship, especially with people with dementia. Also it implies in a positive sense that in spite of the difficulties, the confusion and the 'not knowing', it is important to keep going, to keep searching. To keep finding better and more embodied ways to communicate and to be able to share reflexively with our colleagues, the subjectivity, the intersubjectivity of all that we can discover about ourselves and about those with whom we work.

In summary, the argument presented here in this section is that following the exhortations of Goldsmith (1998) and others, in order for care-staff to be able to better communicate with those in their care, processes of supervision are necessary that focus on embodied, emotional and creative expressive communications. The question remains therefore of how to provide this?

### **7.7.8 Epistemological Problems**

The fieldwork phase presented numerous epistemological problems inherent in studies of this type. These included the problem of how the results of a study of a small group of patients and their care staff could be generalisable and relevant in a wider dementia care context. The main intention, however, was to analyse and use the data sets in relation to what a typical DMP session looked like. What for example, does the Dance Movement Psychotherapist do in a session of this type, also what do patients and staff do and say? These are difficult areas to study; however, ‘without research involving elderly people with dementia it is hard to see how any problems which are unique to this group could ever be investigated or how treatment and care could be improved’ (Watson, 1994, cited in Vass et al., 2003: 27). With this caveat in mind, individual patients in this one session may typify, in certain ways, all other sessions and learning can arguably be generalised and transposed into similar settings with a similar patient population. This does not imply that every person with dementia and every member of staff is the same in other settings. While individuals are unique in their responses, every session will be similar in some respects and different in others. Specifically, this means that in relation to overall structure,

process and identified themes, there will be some generalisable aspects and similarities, whilst the actual content on the day and people's responses to changed content, context and environment will arguably be different. For example, numbers taking part (four) was representative of the typical patient and group number in the ward/residential home setting. It was also not the first session, which would otherwise have made it difficult to generalise outcomes as patients and staff would be unfamiliar with the content, context, values and principles. Two previous sessions on 3rd and 10th April had given patients and staff time to familiarise themselves with me, including the overall therapeutic approach, session content, props and music used which was a significant factor in building confidence through the shared group experience.

Overall, the fieldwork presented significant challenges for me in my current practice about being best trained, best prepared and best able to interpret the meaning underlying communications and behaviour especially when expressed symbolically, non-verbally and in 'embodied' ways. The ability however, to carry out that interpretation, is influenced by what CG Jung has reportedly said, in relation to psychoanalysis and the approach of the Jungian analyst, 'As Jung said so often, the analyst must learn the skills, gather the knowledge, but forget them all when an individual comes through the practice room door' (Evetts-Secker, 2004: 12)

The analytic 'practice room' referred to here is obviously not the same as the group or activity room where DMP sessions take place, nevertheless I think there are important lessons to be learnt here. This reflection on Jung's exhortation by a senior

Jungian Analyst is particularly relevant. Care-staff need to be best trained, best skilled and best prepared to be in the group room and paradoxically to forget it all when they are in the room running the group. This I would argue enables them like the therapist or analyst not to be burdened in the group session by that which is not of the present-moment. This means they are better able to respond to what is of the *immediate* present and expressed by people with dementia in embodied ways. While the work of the Dance Movement Psychotherapist is highly skilled and a specialist area of expertise, care-staff still need to be able to make sense of the communications as best they are able, being present, remaining open, patient and tuned-in towards that which at first they may not understand in the manner described previously by Evetts-Secker. This aspect of session facilitation and leadership is I would argue also generalisable.

I have previously suggested that there will never be enough practising Dance Movement Psychotherapists to meet the need for this kind of psychologically framed approach; staff and management will need therefore to obtain and provide the best kind of training, support and supervision for improving communications as they are able. My proposal for the creation of 'Creative Care' (see Chapter 8 section 8.3) aims to go some way to addressing this situation, contributing practically and experientially to the training of staff in ways proposed here in this thesis.

### **7.7.9 In conclusion**

Lastly, I would like to end this chapter with an exhortation from the current Archbishop of Canterbury: 'Perhaps that is the real challenge of dementia care: to

hold up a picture of what language actually is. Where communication is broken, dysfunctional, turned back on itself, persons are trapped: care for persons is care for their language, listening to the worlds they inhabit (to their souls) so as to engage with other worlds – neither reductively or collusively’ (Williams R, 2005, cited in Hughes et al, 2006: 27). Here Williams exhorts us all as care-staff, health-care professional, clinician and arts therapist to be best prepared and able to take that vital and essential step that care for persons with dementia means being better able to listen for ‘the worlds they inhabit’ in order to be better able to engage with them in those worlds. Here is a strong and important link to one of my central arguments in this thesis, explored and evidenced here in the data analysis. We need to learn to make otherness and difference and embodied practices the norm rather than the exception in dementia care, however challenging the task. This should enable a fuller, richer and more encompassing attitude to life and the practice of care; by our being better able to understand, cope with and appreciate difference and complexity expressed by way of these other unique personal worlds. The next chapter will draw the thesis to a close and attempt to describe how it might be possible to respond to the challenges presented here by configuring what I’m calling ‘Creative Care’. It represents a call for a different, more embodied and creative approach to improving the quality of care practices, drawing on the communications, behaviours, relationships, themes and meta-themes identified, analysed and discussed here.

## **Chapter 8 – Creative Care: a new embodied framework for dementia care**

### **8.1 Introduction**

In this chapter, I shall draw conclusions from my research and reflect on my findings. I shall also present and discuss a new embodied framework for dementia care that I am calling ‘Creative Care’. This framework has arisen out of previous experience in the field and also in response to my studies and researches presented here. This is an approach to improving the quality of life for those in care by setting out a well-argued case for how the creative arts, including DMP, can re-vision the care, treatment and well-being of people living with dementia in the UK. It sets out a challenge to the dementia care community to respond more creatively and more effectively to the emotional and communicative needs of people living with dementia and their care-staff; congruent with the charge discussed at the end of this thesis to help create ‘an immeasurably richer conception of the healing of the mind’ (Kitwood, 1997a: 144). The ideas presented here could also be taken and adapted for use in people’s own homes by enterprising individuals including carers themselves.

The thesis has charted a complex course between different academic disciplines and professional practices, on the subject of aiming to better understand the impact of DMP on older people living with dementia and their care-staff and the relevance or otherwise of ‘embodied practices’. It has been influenced by the study of Anthropology, Ethnography, Dance Movement Psychotherapy, Analytical

Psychology, Management Development and the contemporary professional practice of Person-Centred Care including Dementia Care Mapping. It could be argued that this bold academic attempt, drawing on these different disciplines, is bound to fail on grounds that the depth of knowledge and understanding required about one alone, is enough of a task; without complicating and possibly weakening the argument by involving several others that weave, like warp and weft, around each other. I have taken this risk, spurred on in part by the fact that my pursuit of knowledge has a specific purpose: to learn more about the experience of older people living with a dementing condition in order to be able to contribute to *improving* it. Also because the context including the different strands of dementia care within which the questions are located, demand width, breadth and scope of enquiry in order to answer them. My search for knowledge is grounded too in the reality of working everyday in my Clinical Practice as a Dance Movement Psychotherapist within the NHS, repeatedly witnessing the on-going impact of my own and others values, beliefs and care practices. My practice has changed for the better in relation to what I have been able to learn and apply during this time.

Following the study of cultural anthropology, the concept of crossing boundaries or learning to 'build bridges of understanding' fitted well with the existential idea that working with people with a dementing condition (especially in the later stages) means working in the 'here and now'. By doing this care-staff find themselves more able to witness and work with remaining potentials requiring professional and personal levels of openness to individual expression, to patterns of communication and behaviour and to 'difference', 'otherness' and 'strangeness' as previously described in Chapter

2. These levels of openness attitudinally require a major change of approach by those working in the field, a change that is broader, wider, more human and more accepting of difference and eccentricity. This process could also be described as contributing to reducing the stigma of forgetting associated with it, where ‘madness’ (sic) is not seen as mad. The change also posits, by way of the image of ‘building bridges of understanding’, that there are many different ways, or ‘bridges’ through which to be able to build relationships and work very differently with the person.

I conclude in this final chapter, therefore, that this transcending of disciplinary boundaries, this fundamentally existential approach to knowing and ‘not-knowing’, opens the way to improving knowledge and understanding; about how best to work more openly, more existentially, more creatively and imaginatively with people in this condition. It also opens the way for other researchers to build on the questions raised here, to continue working to better understand the impact of DMP on people living with dementia.

The approach that I describe as ‘Creative Care’ does not deny or demean the cognitively based ‘bio-medical’ approaches to the assessment and treatment of people with dementia; it offers instead a way to extend the boundaries of current practice making them more embodied, psychotherapeutically informed and relevant. ‘Creative Care’ is also supported by a powerful exhortation from an acknowledged expert in the field, charging us to continue to find ways to develop work in this field: ‘(w)e are morally obliged to continue working in extending our limited understanding, developing our embryonic skills and taming our deep anxieties’ (Gibson, 1999: 24).



## **8.2 The way forward for dementia care**

In this thesis I have discussed in detail the impact of a group DMP session on people with dementia and their care-staff. I have investigated the use and importance of embodied practices both within and outside of the session and how these have contributed to achieving significant outcomes. I have discussed and analysed the results that emerged from the fieldwork and now need to synthesise the results by way of constructing and projecting the implications forward for the dementia care and DMP fields.

This study comes at an urgent time as the care of people with dementia increasingly comes to the attention of government, the press, and the Department of Health with the publication in January 2009 of the first National Dementia Strategy (Dept. of Health, 2009). Significant efforts are now being made to formulate a strategic and planned approach at national level to better regulate and develop the industry, with reference to a wide evidence base and the implications of the projections for ever increasing numbers of people with dementia (see Chapter 3). These projections include a very significant economic burden on the State, which it is hoped the National Dementia Strategy can reduce significantly if the measures recommended in it are fully implemented.

In this thesis I have transcended disciplinary boundaries, I have used anthropological insights to broaden, deepen and generally open up my sphere of enquiry, and I have in the process drawn on the work of many pioneers in their respective fields. This has demanded an openness to enter completely new territory for me. I had no idea when I

started out that it would be anthropology and ethnography together in their different guises that would offer so much new knowledge by way of helping me open up my understanding about the effects of arts psychotherapy and DMP in particular on the field of dementia care. Both disciplines have offered important insights to reflect on how we might better get to know what having dementia syndrome means, to better appreciate its unique and existential nature for each person living with the condition and to offer practical solutions for improving relationships. No two people are alike in the way they cope and respond; whilst this is not in any way to diminish its severity and debilitating neurological and cognitive effects on the person and their circle of family and friends, it is to offer a *counter-balance of hope* in place of despair, hopelessness and helplessness. It is still possible for the person in spite of severe cognitive and other losses to be reached, touched and responded to by way of the body in *addition* to any remaining routes for communication.

I have gradually built a strong case here that the use of embodied practices can add to improving the quality of care and particularly of relationships, revealing there is still much to re-discover, to re-member and relate to, that may previously have been thought lost to the person. This study represents a call therefore to all working with people living with dementia, *not* to give up in their on-going attempts to maintain and develop their relationships right to the end. Far from it, it means that for the frailer person and the more severely confused, the greater the need to go by way of all the senses, or whatever senses remain accessible to the person. The approach must be authentic, embodied, emotionally and psychologically congruent and honest, with the intention at all times in, ‘finding the best possible route to supporting their struggle to

be heard' (Ward et al, 2002b: 36) without coercing or patronising the person in the process.

The outcomes of this study mean that care staff should be given opportunities through training and development initiatives, both on and off-site, to learn about how they can become more attentive to the use of these creative and embodied practices, in ways that take their work and practice forward. Cognitive loss and memory problems should not be used as excuses, that because of them the person can no longer be communicated with or related to. This research highlights the challenge to care-staff to find more value in dementia, providing different and more embodied ways of relating that are a step forward in locating 'the body' epistemologically at the centre rather than the periphery of knowledge in dementia care.

Care homes and the wide range of employing organisations should consider how the embodied practices described here could dovetail into everyday care-planning approaches in line with both Person Centred and Relationship Centred Care, neither epistemology clashing, in my opinion, with the other. Care staff for example will be able to *stop* ignoring non-verbal, emotional and body-oriented communications and be able to *start* paying greater attention to the emotional and the embodied and its impact on the person and their care relationships with them. Care staff could also be facilitated to continue doing what they are already doing but to do it differently in relation to this new embodied knowledge, expressed here in the form of 'Creative Care'. The results of this change in care practices should see increased job satisfaction, improved staff morale and perhaps even reduced rates of absenteeism

and sickness generally. Cost implications on care budgets are not great in terms of acquiring compact disk players, compact disks, various props and resources such as elastic, scarves, cloths and ribbon-sticks to name a few. Financial outlay will be needed in terms of care-staff training and the next section details the implications of what that training could entail, in order that these recommendations can be grounded realistically in everyday care practice. Recommendations for 'Creative Care' do not detail the costs for a training programme but they are not excessive.

It has become clear during this study that the emotional impact on care-staff was considerable as they opened up to learn more about the people in their care and *not* in the context of a bio-medical paradigm. The knowledge and experience gained can be shared and used creatively in many different ways, both within and outside of the session, as I have reported in relation to the use of embodied practices and improvement in the quality of relationships particularly. This latter aspect is one of the major successes that this study has been better able to highlight, including the many different ways through which the person with dementia can be reached in spite of many accumulated losses. If the person can experience and palpate care-staff's genuine attempts to be in relationship with them, better meeting their emotional and psychological needs, the greater the chance for an all-round improvement in the quality of care (Sheard, 2008a).

All together the outcomes of this study are a significant development in improving knowledge about people currently living with dementia, those who care for them and

the possibilities for taking dementia care forward through the creation of ‘Creative Care’.

### **8.3 Implications – Introducing ‘Creative Care’**

The concept of ‘Creative Care’ has arisen in response to the researches carried out in this study. It seeks to build on the conclusions identified in this Chapter and provide a framework that transcends disciplinary boundaries and builds bridges between people where embodied and creative care practices combine to offer a care environment more suited to meeting individual need. If it is to succeed, this approach must have the individual person with dementia at its heart, working together in creative partnership; skilfully, flexibly, with the family and with care-staff wherever possible. What is described here is ‘feelings based’, experiential, embodied and psychologically informed with the intention to weave together the many different threads and strands presented in this thesis leading metaphorically speaking to the creation of a ‘garment’ – ‘Creative Care’, presented as something that one wears, that is close to the heart of who we are as people, and a ‘garment’ so to speak, that can easily be accessed and worn on a daily basis. Put another way, it is about coming from different positions (Samuels et. al., 1986, Best, 2003) that have different effects, acting as different ‘triggers’ into the person’s world, while accepting at all times the reality of their lived and embodied experience, however challenging or difficult that may prove to be in practise.

Some of the latest thinking in neuroscience concerns the contentious proposition that individual cells in the human body have their own locus of intelligence including

cellular memory and particular attributes that are peculiar to and separate from any over-arching function of the human brain (Ford, 2006, see discussion in Chapter 3, section 3.4). This research in the biosciences has particular significance for the development of embodied practices as it may help to underpin why and how they may be of particular significance to a person for whom brain function is impaired. I build on this argument by asserting as a Dance Movement Psychotherapist that I have witnessed during this study examples of when the touching of a hand seemed to have an observable link to the singing of a hymn for a participant. The trigger did not seem obvious at the time and the question about what may have triggered the hymn singing response has interested me since. Could it be explained with reference to the concept of a cellular awareness triggered through touch? It is not the purpose of this thesis to develop this line of enquiry further, merely to suggest that it may present future researchers in this field with new pathways, in order to explain neuroscientifically the role and function of cellular intelligence especially for people with cognitive impairment.

The development of 'Creative Care' has also been spurred on by my own life's journey these past eight years of study and research, I have had a strong personal motivating factor, profoundly influenced by witnessing the slow and inexorable cognitive decline of a brilliant senior Jungian Analyst, herself now living in a care-home with a dementing condition. I am, by way of a personal response to her situation, and her increasing frailty and confusion, highly motivated to learn and do whatever I can that might have the effect of supporting her 'well-being', reducing any suffering and contributing to alleviating the effects of long periods of seclusion in her

room. The context from which this response emerged came out of my past analytical work with her and our dialogues together. She first alerted me to questions concerning the ‘not-yet-known’, the deeper symbolic meanings underlying the person’s experience of the condition, their living ‘embodied’ reality, and how I might, as a practitioner and psychotherapist, work more effectively with those aspects of communication, behaviour and presentation that I didn’t necessarily understand at first encounter. How, for instance, as a Dance Movement Psychotherapist I might remain open to a growing subjectivity, inter-subjectivity and reflexivity about this ‘not-knowing’? In the context of therapeutic practice this means not to rush to conclude, but rather to allow wherever possible the answer to find me. This implies acceptance of ‘not knowing’ as paradoxically important to the process of knowing, acknowledging that there is not one ‘single’ way but in fact there are many ways through which to engage each person and come to understand the meaning underlying the communication. There are indeed many strands of ‘warp’ and ‘weft’ left which inter-weave and our work is to find those that best suit the person we are working with at the time, while at the same time remaining alert to any patronising behaviours as previously described (see section 7.3.1).

The process described above is contrary to accepted wisdom about the importance of ‘knowing’, of clarity, and the need for certainty in assessment, immediacy in decision-making, especially in relation to clinical processes of treatment and care. This approach is in contrast to the rigorous demands of the ‘bio-medical’. It does not represent rejection of it, rather acceptance of ‘not knowing’ as a reality, rather than a phenomenon to be avoided. This means being able to accept the following states as

possibly unavoidable: lack of clarity in short-term memory; confusion in recognition of body states; a change of mind; poor speech and language and other disabilities, as the 'norm' rather than the exception. Effective clinical practice has paradoxically therefore to accept 'not knowing' as a reality, whilst at the same time still taking disability in function and cognition into account and being able to represent the person and their condition as accurately as possible. This challenge is echoed in the following: '...with Alzheimer's disease, the caregiver's challenge is to escape the medical confines of disease and to assemble a new humanity in the loss' (Shenk, 2002: 93). If Shenk is right and I think that he is, then 'to assemble a new humanity in the loss' (op.cit), starts with this acceptance of the need for a different, more human, *subjective, inter-subjective* and *reflexive* approach to clinical process, offering for the person an important sense of being 'met' and 'heard' more fully, resulting in better outcomes for all involved.

In response to my personal journey in Analytical Psychology I have been changed quite remarkably, leading to a transformation in my experience of the therapeutic relationship coupled with a growing sense of urgency that little time is now left to be with the person during her last years as friend. Paradoxically I am now better able to listen to and meet the person where they are, without being as fearful or anxious as I was about doing something 'wrong'. By this I mean that I have learnt and am continuing to learn how to tame my own fears and anxieties including my experience of this 'not known-ness'. I have gradually learned how to: 'adjust to the trajectory of the illness, cope with the changes, accept the manifold losses and deal with their own grief' (Gibson, 1999: 21). I too am having to deal with my own sense of grief in



relation to the ex-Jungian Analyst described above and also when day-attenders with whom I work, suddenly stop attending, or go into long-term care. This has also meant becoming less dependent on the need to have an ‘answer’, quieting in the process those inner anxieties which I may unconsciously project onto others, thus deepening the experience of our meeting and their and my own humanity. This is not to diminish the importance of developing and maintaining sound clinical judgement; it is about being more accepting of ‘difference’, ‘otherness’ and ‘confusion’, however and whenever expressed and especially in relation to the clinical practice. Clinical assessments need to be well formed and the challenge is to take these unique differences into account without excluding them in the frame of assessment, thus resulting in better clinical outcomes. It means also for the clinician to remember to go by way of retained and remaining embodied abilities and remaining potentials to offset the cognitive deficits; underpinning the importance of the embodied lived experience and of ‘personhood’ along the way.

### **8.3.1 Implications – Making ‘Creative Care’ a reality**

‘Creative Care’ aims to enable key elements of embodied, therapeutic and creative practices discussed and analysed in this thesis to be synthesised into a programme of training to improve the quality of lives of people with dementia. It aims to translate theory into practice providing a platform on which care-staff in a wide variety of settings can be assisted to develop their existing provision of creative and activity based programmes. The intention is to locate this approach within the training and development of care-staff, supporting them in their everyday care practices using the

‘Meta-Themes’ diagram as a valid framework within which to conceptualise and ground the approach (see Chapter 7, diagram 2). The ‘Meta-Themes’ have emerged as a result of the fieldwork undertaken for this study, so the proposed programme described here aims to ‘build bridges of understanding’ between the theoretical, the academic and the practical in this thesis and care-staff working in the field. The concept of ‘Building Bridges of Understanding’ is at the centre of the diagram, being at the heart of the approach, in close relationship with five other key concepts that cluster around it, each of which has emerged out of the fieldwork aspects of this study. These five concepts are:

- 1) Building relationships through embodied practices.
- 2) Maintaining identity/personhood.
- 3) Providing opportunities for staff training and development.
- 4) Supporting emotional communications.
- 5) Providing enjoyment and supporting observed ‘well-being’.

These different concepts are held together metaphorically speaking by the ‘glue’ of eight relational and communication processes that are taken together: subjective, inter-subjective, reflexive and dialectical. These processes include: interpreting, clarifying, intuiting, repeating, differentiating, supporting, nurturing and encouraging. Care-staff would be encouraged to explore and develop their skills in using these processes in relation to running a programme of sessions of this type. They would also be expected to learn how to prepare, plan, deliver and evaluate sessions and their outcomes for people with dementia.

‘Creative Care’ does not rely on the purchase of expensive equipment but aims to give care-staff a greater range of skills and abilities, including embodied practices in working more effectively with individuals and groups. The approach would aim to:

- 1) Raise the quality of care in a wide variety of settings by improving staff/resident, patient/ staff communications and relationships within a context of ‘Relationship-Centred Care’ (Tresolini and the Pew-Fetzer Task Force, 1994).
- 2) Provide opportunities for the person with dementia to be more actively involved in ‘re-membering’ their own lives (‘revealing the hidden humanity’, Coaten, 2002: 386) involving more one-to-one work and the lives of others in a group-work context (social interaction).
- 3) Seek at all times to support, maintain and foster observed ‘well-being’ (DCM, Kitwood and Bredin, 1992b), for people with dementia and staff alike.
- 4) Create opportunities for care-staff to learn first how to value, express and develop their own creativity through active participation in these arts and embodied practices, then how to value, express, support and develop its growth in those for whom they care.

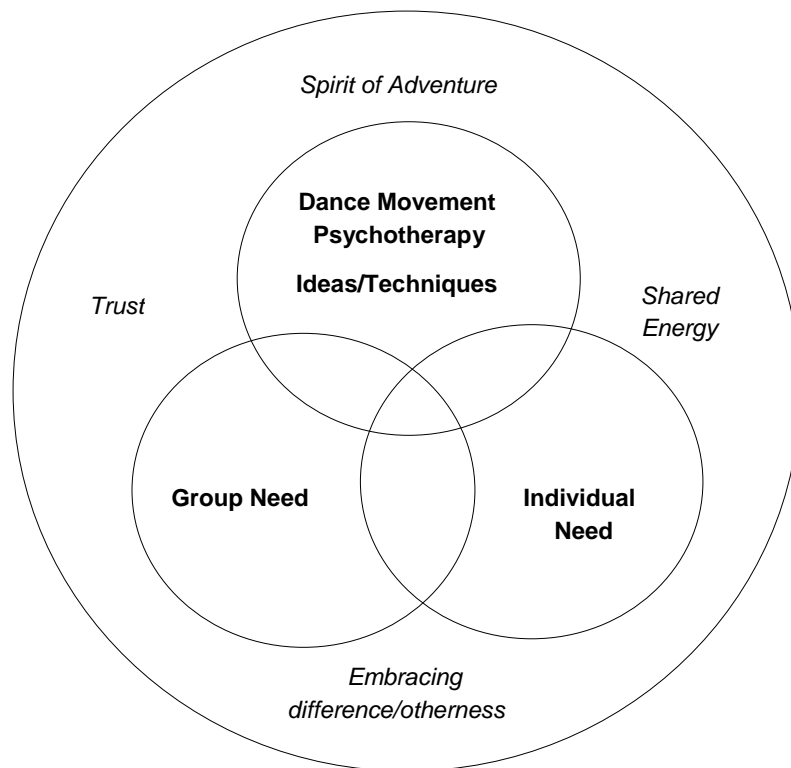
The programme would also involve introducing participating people with dementia to a range of accessible, meaningful and enjoyable (Harmer and Orrell, 2008) arts activities that enable them to re-member, reflect on, and share their past life

experiences with others through: creative-writing (Killick, 1997b), music (Aldridge 1998, Bright 1988, Ishizuka 1998, McCloskey 1990, Prickett and Moore 1991, Sacks 2008, Threadgold 1995, Whitcomb 1994), movement and dance (Coaten 2001, 2002, Crichton 1997, Donald 1999, Gibson 2002, Greenland 2000, Haisma 2008, Hill 1999, 2001, Levy 1988, Meekums 2002), song (Brown et al, 2001, Gotëll et al, 2003, McMorland, 1998), reminiscence (Schweitzer, 1998), and other embodied practices (De Hennezel, 1997).

Diagram 3 below provides a visual illustration of how ‘Creative Care’ can be framed at practice level in terms of the overall atmosphere of care-staff aiming to create a spirit of adventure, shared energy, trust, and an embracing of difference and ‘otherness’ however expressed. Within the culture of the group can be found three interlocking circles; the circles dissect each other at a middle point representing visually the need for the three main factors to be in dynamic balance.

**Diagram 3**

**Moving towards Creative Care**



The aim therefore is to achieve a creative and dynamic balance between the needs of the activity, here represented by DMP, the needs of the individual and also those of the group. The nature of the activity does not have to focus on DMP, in part because as has already been argued, the type of activity isn't necessarily what matters the most, as much as the quality of the experience (Harmer and Orrell, 2008, Perrin, 1998). Also in part because the nature of the DMP session presupposes that a Dance

Movement Psychotherapist will run it. This is a potentially unrealistic expectation (much as I would like more Dance Movement Psychotherapists to be working in this way) because in relation to the numbers of trained, experienced Dance Movement Psychotherapists available, demand for creative and therapeutic activities in this area is likely to be high. In effect, my assumption here is that there will not be sufficient supply to meet demand and therefore the focus is best placed through training and the implementation of 'Creative Care' in the work place.

The intention for 'Creative Care' is also that care-staff will be trained by me to deliver sessions of this kind. This training will enable care-staff to experience creative and embodied activity for themselves first, exploring the processes previously described in Diagram 2 before going on to provide it for others later. It is essential that care-staff be emotionally, psychologically, physically and cognitively touched by way of experientially interacting with the creative media first, before expecting them to be able to relate to and develop its use with people with dementia later on. Without this experiential and embodied understanding on the part of care-staff it is unlikely that this approach will thrive. Care-staff may seek to copy and mimic what they have learned from me rather than take it as an approach that they can in time make their own. This ignores the impact of the organisation and management on actively supporting this approach and enabling staffing rotas to implement coupled with the resources to provide it.

A typical training programme of 'Creative Care' would last approximately nine weeks. There would be a combination of off-site training sessions at a suitable venue,

once a week for four weeks, coupled with on-site sessions at the care settings involved for the same period. During this first month there would be a total of four training days covering the subject matters discussed here, including knowledge and skills about how to run, evaluate and continue a 'Creative Care' programme. Also during this first month, care-staff in training would be asked to be participant-observers in weekly group-based sessions in their own care setting with residents/patients that they know well. The combination of off-site training and on-site sessions enables the creative work to be experienced and explored off-site followed by implementation on-site, with patients/residents they know and who know them. On-site sessions are initially run by me in the first month, with the intention to hand over the responsibility for planning and leading the groups to staff in training once the first month is completed and for a further consecutive four weeks.

At the end of the last four sessions (week eight) during which care-staff have practised their skills, there will be a remaining week for staff to collate photographs of their sessions and evaluations in order to mount a display of work done. At the end of the ninth week a Review Day is held where in the morning care-staff discuss progress and achievements, set-up their displays around the room and prepare to make presentations of their achievements and those of their session participants to senior members of their organisation come the afternoon. The presentations and display boards enable a flavour of the approach and work done to be presented to those who may have funded the programme, and also to be displayed at a later date in the concourse of the home or the hospital ward for carers and family to view. Equally senior management can experience and learn as told in the words of their staff how

effective the training has been; they can also respond to what has been said supporting the actions of their staff, at the end of which Certificates of Attendance may be presented, by way of acknowledging participation and achievement.

Finally, care-staff as a result of this 'Creative Care' approach should be better able to recognise and to use their own creative and latent talents in their work, having gained in confidence about using them. They should also have better understanding and knowledge about how the creative arts stimulate and empower people with dementia to take a more active part in the life of their care home or setting. They should also be better equipped with the skills and knowledge to further develop their activities programmes through the application of these skills.

The training programme described here lasts over a period of nine weeks and is a practical example of how the 'Creative Care' approach works. It is only an example and it represents an ideal time frame. In practice there are many competing variables that determine the length of the programme and budgetary concerns feature high in this respect, meaning that a nine-week programme may not be realistic from a cost point of view. Again from a budgetary perspective each setting and the two nominated staff participating would be provided with a basic kit of props for use in these sessions, which they could use immediately and also add to over time, developing their resources for this work in the process. A nine-week programme should work well allowing time for the approach to bed in to the setting and its staff and residents.



### **8.3.2 Transcending disciplinary boundaries**

In this thesis I have been most interested in the question of how as care-staff and clinicians we can allow ourselves to be more open to ‘the other’, to difference, strangeness, and ‘otherness’ as so often expressed by the person living with dementia in their communications and behaviour. How can we better understand, better able to surrender to these communications and expressions of ‘personhood’, and by so doing meet the person in their world and on their own terms. This means acknowledging the difficult challenge set by Goldsmith (1996) that we have a profound responsibility on us to do this and that set by Gibson (1999) that if nothing else, we are morally obliged to do so. This challenge is also framed within a context of care-staff often stretched emotionally, psychologically, physically and intellectually in the caring process, barely able to cope in fact. There is very little if any training in communications, in creative practices, in group-work, in support through supervision, with staff also on very little pay.

In attempting to answer the fundamental question, about how to go about improving the quality of lives of people with dementia in care, my researches have led me to transcend disciplinary boundaries: between the embodied and the disembodied; between bio-medical science and the bio-psychosocial; and of particular interest here between dementia-care and the disciplines of anthropology and ethnography. I have found the anthropological concept of ‘building bridges of understanding’ between that about which we know and that about which we don’t, most valuable and central

to my researches in coming to appreciate otherness and difference, as the norm rather than the exception (Schultz and Lavenda, 1990).

In my own words I have sought to transcend boundaries, building bridges and relationships as I go through inter-disciplinary practices and study in order to help weave together and make sense of the fragments of thought, behaviour and communications that still exist for the person with dementia and which I have found very perplexing. I have sought, 'to find the harmony within the dissonance of dementia, (about) screening out the static and creating genuine opportunities for drawing on old as well as new creative expression...' (Gibson, 1999: 23). For me the need in clinical practice is a predominantly palliative rather than treatment oriented one, to maintain, support and enhance 'well-being', encouraging personal and inter-personal communications and behaviour wherever possible, especially of the embodied kind, bringing a sense of hope and awareness of remaining potential in contrast with a panoply of loss. This means the ability when necessary to transcend inter-disciplinary boundaries as well as those between people. As Hughes et al. (2006: 35) have argued in their remarkable work: 'our substantive conclusion is that people with dementia have to be understood in terms of relationships, not because this is all that is left to them, but because this is characteristic of all our lives'. Developing our relationships with people with dementia and those who care for them means that we have to be as best prepared as we can to meet the challenges presented to us; best prepared to venture into new territory by way of transcending disciplinary boundaries; while remaining open to the present moment, to 'Being', and what transpires for us and our informants in that moment (Sheard, 2008a).

#### **8.4 Concluding thoughts - Changing the culture of care**

I have argued in this thesis that more needs to be done in improving communications and relationships in dementia care and in the use of the arts and DMP in particular to help create the changes that can improve the quality of life and care for the person. I have argued for more relational, more subjective, more inter-subjective and reflexive approaches to the provision of care informed by ethnographic and anthropological insight. I have discussed the importance of building bridges of understanding linking anthropological insights, techniques and approaches with DMP and with contemporary thinking in the dementia care field. These I have argued can enable practitioners to be more reflexive, more questioning, more thoughtful, more creative and more able to meet the needs of people with dementia as a result. I have also made strong links between what the anthropological/ethnographic literature describes as an 'anthropology of the senses' (Howes, 1991, cited in Classen, 1997: 407), with what the dementia care literature refers to as 'The Senses Framework' (Davies et al, 1999, Nolan, 2007, cited in Nolan et al, 2008, Nolan et.al. 2006 cited in Nolan et al, 2008) within the context of Relationship Centred Care (Tresolini and the Pew-Fetzer Task Force, 1994, Nolan et al, 2008) to effect these changes. Those with their needs well met are likely to have more confidence and emotional connection with their care-staff and will thus be *less* likely to resort to what are described as challenging behaviours (Cohen-Mansfield et al. 1989, 1990), including screaming and shouting. Any reduction in the amount, frequency or duration of challenging behaviours will put less physical, emotional and psychological stress on staff. Staff who develop a special

understanding of the *'lived experience'* of dementia and the skills to support broader needs can make a significant difference to residents lives (Bruce, 2002: 335). What becomes vitally important in this relationship-centred view of dementia care is the importance of finding, identifying and using a wide range of appropriate and accessible methods and techniques for facilitating communication. Care staff will need to be more skilled at communicating and I have proposed that doing this within the framework described here as 'Creative Care', could make an important contribution to raising the quality of care in the light of the challenges currently presented (Dept. of Health, 2009).

I am under no illusions that interventions however demonstrably creative or valuable in themselves involve cultural change in the organisation and cannot be accomplished effectively without the support and understanding of management and the organisation that provides the care. Even then there may be procedural and policy barriers (Hill, 2004: 212) or underlying 'values as barriers to person-centred care' (Hill, 2004: 216), or equally important the hegemony of the bio-medical model inhibiting development (Hill, 2004: 227). Legislative frameworks, where these exist, can help, as can the training and development of staff. However it is also a case of winning hearts and minds of all the key players; ensuring that they have more information about the nature and complexity of contemporary dementia care practice, can see the value of implementing this new approach in the form of 'Creative Care' and are willing to find the funding required to implement it.

I have argued in Chapter 2 that Hanna's comments about the importance of individual and organisational cultures are particularly relevant in this context as they are to my own practice (Hanna, 1990). No matter how hard I try to maintain high quality Dance Movement Psychotherapy work, its success depends to a large extent on the organisational culture, which either supports or rejects it. Without crucial managerial and operational support and leadership from the organisation, embedding the use of the work in the care home, ward or day centre is not possible if neither staff nor manager see the relevance of it. A sensorially oriented anthropologically informed perspective however, dovetails and supports quite organically the sensorially oriented world of DMP, within the dementia context finding a home within the dual frameworks of 'The Senses Framework' and 'Relationship-Centred Care'. Together, these present very relevant and helpful theoretical and practical frameworks that together with 'Creative Care' enable those directly involved to a) appreciate the complexities within the process of care; b) equip them to recognise the challenges as well as the opportunities; c) evolve the practice in response to the learning gained to make a big difference to the culture and quality of care.

The care of people living with dementia presents fundamental problems of communication that lead to reflection on the nature and importance of relationship in the context of care. One of the fundamental difficulties within the caring relationship is for the carer or member of the care-staff team *to keep pace* with the changes taking place for the person. Changes can vary on a time spectrum from short to long-term and also in range, intensity and frequency. For example, increasing failure to be able to orient in space and time can for one person be a source of emotional and/or

psychological pain, whereas for another it may be taken less seriously. The fundamental question raised here however is *how* to help carers and care-staff recognise, acknowledge, keep-up-with and act on these on-going changes and their significance for the person. By gaining insight and possible answers to these questions other pathways such as ‘Creative Care’ can be found and evidence gained for building meaning through embodied practices between the care-staff and the person living with dementia.

I have learnt a great deal during the course of my researches and I have been able to put much of what I have learnt into practice, drawing on twenty-two years previous experience in the field. I have been able to transcend disciplinary boundaries, ‘building bridges of understanding’ as I go, and using the knowledge, experience and insights gained to help answer the questions I set myself here. I want to finish this thesis with reference to a call made in the last paragraph of Professor Kitwood’s last book, published just before he died, that for all of us engaged in this work to be able to assemble what he calls, ‘an immeasurably richer conception of the healing of the mind’ (Kitwood, 1997a: 144). We are called to do so, ‘because the reconsideration of dementia invites us to a fresh understanding of what it is to be a person’ (op.cit.: 144). That ‘fresh understanding’ cuts away all that separates us from ourselves and from each other. It asks us to examine and re-examine our underlying beliefs, which supported by the indomitable power of reason, Kitwood wanted to see ‘taken off the pedestal that it has occupied so unjustifiably, and for so long...’ (op.cit.: 144). Kitwood invokes us to assemble a new sentient humanity, in and through the condition, kindling in the process what he calls, ‘our true interdependence’ (op.cit.:

144) as human beings. This call could equally be found in any number of revered religious texts around the world, perhaps echoing Kitwood's own life's journey as priest, psychologist, psychotherapist and academic. This inspiring call is a tribute to the power of what he was able to achieve in the relatively short period of time he spent working and researching in the field. He was in my opinion a true bridge-builder, crossing many boundaries along with his colleagues and breaking taboos (the Romans might have described him as a 'Pontifex', the Latin word for priest meaning a builder of bridges). I draw strength from his work as I too in this thesis have attempted in my way to make many different relationships especially of the embodied and sentient kind. I have sought to identify the ways in which DMP and other art forms help reveal, 'an immeasurably richer conception of the human mind' (op. cit: 144), re-visioning dementia in the process and setting a new pattern of possibilities building on Kitwood's own remarkable legacy.

These are exciting times for the development of the DMP profession within the context of dementia care and I look forward to taking the ideas presented in this thesis further in future research and clinical practice.

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## APPENDIX A / TRANSCRIPT OF VTR

- Session three filmed April 2002
- Venue: NHS Ward for the care of people with dementia
- Film Timing: 10.20am to 11.35am
- Mechanics: One film-maker walking around the room with 1 camera.

- Staff:

R Coaten ( RC/Dance Movement Psychotherapist, DB (DCM Mapper), MM & SD(Staff Nurses), LM, LC, GB Health Care Support Workers

- Patients:

Martin, Valerie, Arthur, Gladys

NB: The left hand column in the text is colour coded to differentiate the three session phases:

ORANGE = SESSION WARM-UP    YELLOW = SESSION DEVELOPMENT    GREEN = SESSION CLOSURE

# Content

Time	Words	Body Movement	Music (Tape/CD/Live)	Notes & Themes
10.25am	<p>RC: 'Hello Arthur'.</p> <p>Arthur: 'How do you do?'</p> <p>RC (to Arthur): 'Hello there, nice to see you'.</p> <p>LC (to Martin): 'Hello pet, this way, you're sitting this side this week. Do you want to sit there? (to Martin – (L does not wait for an answer) I'll swap places shan't I'. <b>Theme 1a &amp; 8</b></p> <p>RC (to Martin): 'Hi Martin nice to see you. How are you? that's a good shake. Excellent, lovely, thanks for coming.</p>	<p>I have prepared the small lounge as a venue for the session. Music, instruments and props are set and ready. Music is switched on to help create welcoming ambience. Scarves are laid across chairs indicating where staff will be seated (pre-arranged with them)</p> <p>Group participants &amp; staff enter small lounge adjacent to main lounge permitting easy access of participants to this session. Arthur enters on arm of LM <b>Theme 5b</b> followed by Martin assisted by LC <b>Theme 5b</b></p> <p>I walk forward to greet people</p> <p>Martin sits in chair – not the one LC had planned for him.</p> <p>Staff talking to each other preparing themselves for the session ( dialogue difficult to record). SD &amp; LC seen moving Valerie's chair to the right to make way for another chair in circle. <b>Theme 1b &amp; 2b &amp; 5b</b></p> <p>I kneel down in front of Martin <b>Theme 1c</b></p> <p>RC &amp; Martin shake hands. M</p>	<p>“ Ho johnny, ho johnny, ho johnny ho' (Tape on) <b>Theme 4a</b></p> <p>↓</p>	<p><b>Theme 1a 'embodiment well supported'</b>. LC allows Martin to sit where he wants not where she wants. Example of good practice in person-centred care – care-staff supporting choice rather than vice-versa (see also Theme 8).</p> <p><b>Theme 1b 'embodiment not well supported'</b>. Valerie is moved a short distance to her right in the chair with no preparatory warning or apparent communication with her about it.</p> <p><b>Theme 1c 'embodied connections-height levels'</b>. Kneeling down means getting onto eye level with the person and this helps non-verbally to support &amp; maintain communication &amp; relationship.</p>

10.30am	<p>That's very nice, thank you, excellent. <b>Theme 1d</b></p> <p>LC: Martin, you enjoy these mornings now?</p> <p>RC: 'Arthur, can you give me your hands (Arthur makes no reply) <b>Theme 8</b></p> <p>RC+ LC + staff all singing <b>Theme 5a &amp; 5b</b></p> <p>RC: 'That's great Martin. That's really good'. <b>Theme 7.</b></p> <p>RC: 'Wo, excellent, lovely. LC: 'Very good Martin'. <b>Theme 7</b></p> <p>RC: 'Let's get the blood through the hands'.</p> <p>Short break in filming</p>	<p>continues the shaking quite energetically with RC. <b>Theme 12</b></p> <p>Valerie seen moving gently side/side Shaking hands continues</p> <p>Martin does not respond verbally to this question</p> <p>I put out my hand for Arthur to hold Arthur looks away across the room &amp; does not move his body. Sits on his hands.</p> <p>RC &amp; LC + other staff begin to hold hands around the circle &amp; gently moving together side to side. <b>Themes 4a &amp; 4b &amp; 18 &amp; 21</b></p> <p>Arthur seen sitting still in chair not moving</p> <p>Group briefly seen moving hands forward &amp; backwards in rhythm. <b>Themes 4a &amp; 4b &amp; 18</b></p> <p>Participants starting to rub/wash hands together – Gladys leaves her chair. <b>Theme 18 &amp; 2a</b></p> <p>Short break in filming</p> <p>Gladys starts walking out of the circle. <b>Theme 2a</b></p>	(SINGING)	<p><b>Theme 1d 'embodied connections – body memory'.</b> I manage to withdraw my hand – I note that the hand shaking was particularly enthusiastic and went on for longer than might have been expected. Question: is this an indication of Martin recognising, remembering &amp; being pleased to see me, which then becomes embodied by him and expressed outwardly to me through the hand shaking?</p> <p><b>Theme 1e 'embodied connections –hand holding'.</b> Making contact non-verbally, by holding a participant's hand in a conscious and sensitive way.</p>
10.35am	<p>LC: 'Alright Gladys?' Gladys: 'Yes, my dear'. LC: 'Do you want to rest your little legs on that chair there?' SD: 'Just watch that scarf there'. <b>Theme 2b.</b> Short break in filming</p>	<p>Short break in filming</p> <p>Gladys starts walking out of the circle. <b>Theme 2a</b></p>	<p>Music stops</p> <p>Short break in filming</p> <p>No music</p>	<p><b>RUBBING HANDS</b></p> <p>Short break in filming</p>

10.40am	<p>RC: ‘Lovely, how about our feet too’.</p> <p>Arthur: says something inaudible.</p> <p>RC: ‘What was that Arthur? (Theme 10 &amp; 14) We’re just doing a little bit of exercise, some warming up.</p> <p>Do you like that sound Gladys?</p> <p>Gladys: ‘Yes’.</p> <p>RC: ‘All the way down the arm that’s lovely.</p>	<p>Short break in filming</p> <p>Group clapping</p>	<p>Short break in filming</p> <p>(CLAPPING)</p>	<p>Short break in filming</p> <p>Theme 2a: ‘Inclusion/exclusion’.</p> <p>Gladys was constantly on the move throughout the session meaning that she chose sometimes to be in the centre of the circle, sometimes on the outside. On one occasion Theme 2aa she walked away through a door into an adjacent ward, down a corridor of about 12 feet in length (not visible on VTR). It was necessary for me to leave the group to follow her and ensure that she was safe and to invite her to return to the group at that time. The importance of this behaviour is that from a person-centred perspective the facilitator needs to be skilled enough to manage the complexities of running the group meeting group needs, while at the same time meeting individual needs. Throughout the session Gladys proved challenging for me in terms of noting her needs, her whereabouts and responding appropriately in engaging her whenever and wherever possible in a range of different activities.</p>
	<p>RC: ‘Come through, (sees Gladys coming back into the circle) Yes, can I introduce you?’.</p> <p>RC: ‘Here we go, some lovely Irish dancing’.</p> <p>LC: ‘Two hands’.</p>	<p>Martin’s feet/slippers seen tapping on the floor. The pace of his hand and foot tapping increases. Martin clapping his hands/feet alternately Themes 4a &amp; 4b &amp; 18</p> <p>Start tapping up &amp; down my arm Theme 4a &amp; 18</p> <p>Group tapping up &amp; down their arms Theme 4b &amp; 18</p> <p>I start to pass a pink elasticated band around the circle for participants to hold. Theme 19</p> <p>Group moving together side/side while seated in chairs. Themes 4a &amp; 4b &amp; 6 &amp; 18 &amp; 21</p> <p>I hold Gladys’s hands and start rocking side to side with her Themes 4a &amp; 4b &amp; 6 &amp; 18 &amp; 21</p> <p>Gladys &amp; I make eye contact (Theme 3), I sing the song to her while kneeling on floor in front of her Theme 1c, then staff lift elastic band over Gladys’s head and she returns to her original seat – with my help</p> <p>I kneel on floor immediately in front of Arthur and sing the words of the</p>	<p>Irish music (tape on)</p> <p>Irish music (tape off)</p> <p>“Ho johnny, ho johnny, ho johnny ho’ starts again</p> <p>(DANCING IN CIRCLE)</p> <p>Evidence at this point of Arthur holding onto the elastic and moving it side to side. All in group now moving with the elastic band and singing. Themes 4a &amp; 4b &amp; 18 &amp; 21</p>	<p>Theme 2b ‘Health &amp; Safety’. SD’s remark to LC about concern for Gladys in case she slipped on a scarf reflects an important theme in all group and 1:1 working with people with dementia. To be very aware of health and safety issues at all times.</p> <p>Theme 3: ‘Embodied connections - eye contact’ as a pre-requisite to</p>

		<p>song ( being played) to him. Arthur responds by saying something to me, which I did not hear. I then sit back on my chair and click my fingers to the rhythm of the music – ‘Oh Johnny, ho etc’. Themes 1c &amp; 3 &amp; 4a &amp; 4b</p>	<p>I get out the instruments including maraccas/shakers and tambourines (live) these are shaken with music still on in background. Theme 20</p>	<p>building relationships with those in the group including participating staff. For people with neurological problems I have found that eye contact enables much to be communicated in relation to how or where a person’s focus may be at any one time. The focus and quality of attention, duration etc</p>
10.50am	<p>RC: ‘Are you coming for a dance?’ (to Gladys). Theme 2aa</p> <p>LC starts singing spontaneously (Theme 5a &amp; 5b): ‘I’m so lonesome every day. I want you to know that, since you walked out on me, for you everyday, walk right back to me this minute</p> <p>... ‘bring your love to me</p>	<p>Valerie moving side to side and also using a shaker in her right hand – appears to be breathing deeply. Gladys again walking in &amp; out of the circle of chairs/listening to what is going on for a bit and then continuing her movements to different places in room. Theme 2a &amp; 18</p> <p>It was at this point in the session that the group were left on their own playing instruments without the facilitator. I went to catch up with Gladys and bring her gently back from a corridor she had walked down into an adjacent empty ward. Theme 2a &amp; 8.</p> <p>Gladys on return sits in the chair I am using next to the CD player.</p>	<p>(MARRACCAS/INSTRUMENTS)</p> <p>Instruments have been passed around. Martin is using the rattle in his right hand. I hold a drum up in front of Martin and he starts tapping the drum rhythmically, quickly at a tempo of about 224 beats per minute continuing at this rate for about a minute. (Theme 4b) Valerie now has a tambourine in her hand and is moving it slowly up and down and to the side. (Theme 4b) She also keeps moving to the right and then to centre. I start clapping my hands in time with the rhythm of the group.</p>	<p>tells a story about a person’s interests, passions &amp; enthusiasm’s which form part of the non-verbal awareness of the person and their range of interests. Holding Gladys’s eye contact at this time contributed to our building a relationship and possibly enabled her to feel a sense of connection and connectedness, to me and the group. One outcome may have been her kissing my hand/cheek later in the session.</p> <p>Theme 4a: ‘Importance of music’ The use of recorded and live music is very important in this context as evidenced by Bright &amp; Aldridge with a variety of identified outcomes and benefits</p> <p>Theme 4b ‘Importance of rhythmic movement’. The early dance movement therapy work of Chace in the United States in the 1950’s first alerted dance therapists to the potential for rhythmic movement as a unifying factor in a group DMT setting. It is very interesting here that Martin with a very diminished vocabulary</p>

	<p>don't send it, I'm so lonesome everyday.....'</p> <p style="text-align: center;">↓</p> <p style="text-align: center;">(singing continues)</p> <p style="text-align: center;">↓</p> <p>Gladys: ' I enjoy you all working'  RC: 'You enjoy working Gladys'. (Theme 10 &amp; 14)  Gladys: 'Mmmmm'</p> <p>RC: 'Oh, thank you for that. I think you're lovely Gladys. (Theme 7). Did it remind you of any songs?'  Gladys: 'Yes, all of Grandad's' Theme 6 &amp; 9b  RC: ' All of grandad's. (Theme 10, 11 &amp; 14) )Ahaa. Yeah, Aaah'.  Gladys: 'Lights, what are you?</p> <p>(the rest too indistinct to make out the words)  RC: ' Did it remind you of anything Arthur? Did it remind you of anything? (to Martin) What did it remind you of?</p>	<p>Gladys leaves her chair and starts walking again. Theme 2a</p> <p>As this song is sung and instruments played I am holding Gladys's hands and rocking side to side with her in the middle of the circle. She makes strong eye contact with me. Theme 3 &amp; 12 &amp; 18 &amp; 21.</p> <p>Gladys moves to the side of the circle as if to leave the group then says something quietly –I motion to the rest of the group to stop playing instruments so I can hear what Gladys is saying to me very quietly.</p> <p>Gladys looks at me .  Gladys moves forward and kisses my left cheek Theme 12</p> <p>Gladys looking across at another person in the room - MM? Who she knows well as one of her carers</p>	<p>End of instrument playing &amp; singing</p>	<p>has a strong sense of rhythm and can hold a regular tempo at 224 beats per minute. I would argue that this exercise at this time in the session enabled him to gain pleasure and a feeling of achievement at being able to complete this activity successfully. Valerie also demonstrated her ability to hold a rhythm, in her side-to-side movements, also in time with the beat or pulse.</p> <p>NB: Theme 5a: 'Importance of singing'. Singing is of particular importance in the provision of activities for people with dementia. Often I have noted in my clinical practice that people with dementia can remember all the words of a song, yet they are unable to remember words and grammar in the context of everyday conversation. Singing also helps the release of emotions, is a failure free activity and contributes to raising well-being and self-esteem as McMorland has pointed out ( 'I hear it in my heart' ref.) See also Themes 5aa, 5ab, 5ac below.</p> <p>Theme 5b: 'Importance of staff contribution to session'.  This is also an example of a member of staff spontaneously contributing to the session by singing a song which she knows and which she thinks Gladys will enjoy. The contribution of all participating staff to the session is</p>
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	<p>Arthur: (says some words that are very hard to make out on the tape) <b>Theme 9b</b></p> <p>RC: ‘Whose birthday card was it? Whose birthday? (I assumed he was referring to his birthday) <b>Theme 10 &amp; 11 &amp; 14)</b></p> <p>Arthur: (says more words in response that are hard to hear). <b>Theme 9b</b></p> <p>RC: ‘George OK. Is George a brother Arthur? Is he an older brother or younger brother? Mmmm’</p> <p>Arthur: ‘Younger’</p> <p>An aside out of view...</p> <p>Gladys: ‘Oh I say’</p> <p>SD: “Do you want all this – the scarf.</p> <p>RC: (to Arthur) ‘Thanks for that, thanks for that. (<b>Theme 7)</b></p> <p>Which is your favourite card up there?’</p> <p>Arthur: mutters some words that are unrecognisable on the tape. <b>Theme 14</b></p> <p>RC: “Mmmmmmm’.<b>Theme 10</b></p> <p><u>Sound of ambulance siren</u></p> <p>RC: (across the circle to</p>	<p>staff. Valerie seen moving to right side then to centre. Martin seen tapping both hands on his knees in time with the music. Then Valerie tiring a bit and not moving to the right side anymore. Then RC’s feet seen moving forwards &amp; backwards, next to Martin’s feet who are not. MM &amp; SD seen moving their feet in time with the music. Martin’s hands seen tapping on his legs. <b>Themes 4a &amp; 4b &amp; 18 &amp; 21.</b></p>	<p>Music stops</p>	<p>‘identity’ is an important matter for the person. Taken simply this comment can be interpreted as the person needing to know where they are in space, in a room or whatever. Often, and in my clinical practice I take this to have more of a symbolic meaning; for example a deeper more existential question underlying this question of location, for example: ‘who am I?’ or ‘I think I may have forgotten myself and need reminding’. Sometimes it is enough to reply by saying the person’s name. I am aware psychologically, that the question of ‘identity’ may underlie the person’s communications and behaviour. At other times they may need to be reminded repeatedly who they are as a matter of urgency. Psychologically this may reflect the person’s need for reassurance that they exist and also how valuable they are to those in their immediate vicinity and their family and loved ones. That they ‘belong’. (<a href="#">Links here to Bowlby &amp; Attachment Theory</a>)</p> <p><b>Theme 7: ‘Giving Praise’.</b> Throughout the session I am aware of the need to reflect back in a positive way the actions, behaviours and communications I see, hear, feel and intuit. This can be described as the glue that holds the session together. It comes partly from experience, partly from knowing how hard it must be for</p>
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<p>11.00am</p>	<p>Gladys) <b>Theme 13</b> ‘ Oh Gladys you look beautiful. That’s a good wash.’ Gladys: says something inaudible on tape. <b>Theme 14</b></p> <p>RC: ‘I wouldn’t have said that at all. I would have said you look like a film-star a movie-star. (Aside to LC) : ‘ one of the um songs from the shows’. Gladys you’ve got a twinkle in your eye Gladys ( To LC) ‘Can we sing one of the songs from the shows. Mmm let’s see – that might go with how you look Gladys. How about this one?’ ( RC starts singing to Gladys and pointing to her). <b>Theme 5a &amp; 5aa</b></p> <p>RC: ‘Put your arms around me honey, hold me tight, huddle up and cuddle up with all your might. Oh, Oh, I never knew any one like you.’</p> <p>(LC then keeps the ‘kettle boiling’ by singing another song straight away without a pause → <b>Theme 5a &amp; 5b</b>)</p> <p>LC (singing): ‘All I want is a room somewhere, far away from the cold night air, with one enormous chair, Oh, wouldn’t it be lovely. Lots of chocolates for me to eat, lots of fires making lots of heat, warm hands, warm face, warm feet, oh wouldn’t it be lovely.’</p>	<p><b>(SINGING &amp; RIBBONS)</b></p> <p>I move down onto the floor towards Gladys still singing to her and she leaves her chair opposite me, moving towards me in the circle. She then sits back in her chair. <b>Theme 1c</b></p> <p>RC holding hands with Gladys in the middle of the circle and rocking side to side. Martin starts clapping spontaneously then stops. <b>Theme 4a &amp; 4b &amp; 6 &amp; 18 &amp; 21</b> Gladys leans forward and kisses my hands at this point. <b>Theme 12</b></p>	<p>Singing starts</p>	<p>some people to take part in group based activities. It involves witnessing, recognising and valuing individual and group contributions however small, celebrating success at every level. For people experiencing cognitive loss and loss of independence in everyday living, activities that focus on success and achievement contribute to a culture that values the person and any contribution they feel able to make.</p> <p><b>Theme 8: ‘Giving Choice’.</b> It is vital to enable real choice for group members at all times and to respect a decision to take part as well as a decision not to participate. Given how frail and vulnerable people in middle to late stage dementia actually are, it can be very easy to ignore or not notice a person’s verbal or non-verbal communication about not wanting to take part. By not respecting choice we diminish ‘personhood’ for all taking part. It is therefore vital that group facilitator’s respect individual choice and decision making at all times and that they constantly monitor and remain alert to their own body language and communications and how these are being interpreted.</p>
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	<p>RC (to Valerie): ‘ oh, thank you, thank you’. <b>Theme 7</b></p> <p>RC: ‘What’s your favourite colour Valerie?</p> <p>Arthur (aside): ‘What’s my favourite colour?’ <b>Theme 9a</b></p> <p>LC: ‘ She likes pinks and violets but we haven’t got any, have we Valerie? Will you have lemon?</p> <p>RC: ‘Will you have lemon? <b>Theme 11</b></p> <p>Arthur: ‘Lemon’ <b>Theme 9a&amp;9b</b></p> <p>RC: (to Valerie) ‘Will you have lemon? It goes with your green top. There we are, brilliant.</p> <p>Varied conversation all at the same time/very difficult to distinguish: duration 10secs approx</p> <p>RC: ‘Can I give you a red Arthur? No, alright’.</p> <p>Arthur: ‘No’ *</p> <p>RC: ‘ I’ll put that down there Arthur’. <b>Theme 8</b></p> <p>RC: ‘ Yes, great, ok, thank</p>	<p>Cut to RC standing holding ribbons on sticks (prop) for people to choose which ribbon colour they might like <b>Theme 8 &amp; 19</b></p> <p>RC handing ribbons to Arthur Arthur nods head left/right indicating no</p> <p>I place a red ribbon at Arthur’s feet – in case he might decided subsequently to pick it up and use it</p> <p>MM seen rotating a ribbon stick next to Gladys ( so she can see it) Gladys seen gently folding red ribbon around the ribbon stick. <b>Theme 5b &amp; 18 &amp; 19 &amp; 21</b></p>	<p>End of singing</p>	<p>* I sensed this as an important non-verbal statement by Arthur in not wanting to participate.</p>
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<p><b>11.05am</b></p>	<p>you...’ – tape changing</p> <p>Singing (several voices inc. RC &amp; LC): ‘ Oh when the saints go marching in, oh when the saints go marching in, I want to be in that number when the saints....(indistinct). I want to be in that number, oh when the saints go marching in’. <b>Theme 5a &amp; 5b</b></p> <p>LC: ‘Do you know this song?’</p> <p>RC: ‘Well’ LC: ‘ Catch a little fishy oh.. RC: (Laughing) ‘ That’s lovely LC, yeah. (<b>Theme 7</b>) Just got this idea of fishing Martin, sort of.’ Gladys: ‘Oh, how dare you? <b>Theme 9b</b> Arthur: ‘How dare I?’ <b>Theme 9a</b> MM: ‘ Darling, how dare we what Gracie? <b>Theme 5b &amp; 10</b> Gladys: ‘ Go fishing?’ <b>Theme 5b &amp; 10 &amp; 14</b> RC: ( still laughing) Arthur: ‘No, not go fishing’ <b>Theme 9b</b> RC: (still laughing) (indistinct dialogue 2/3 secs) RC: ‘Going through there’.</p>	<p>Valerie seen moving ribbons up &amp; down in her hands &amp; moving side to side. <b>Theme 4a &amp; 4b &amp; 18 &amp; 19 &amp; 21</b></p> <p>Arthur not singing – seen looking intently at something on the floor, tambourine in hand?</p> <p>Group seen moving ribbons up &amp; down. Martin moving ribbon up &amp; down very quickly (similar to previous rhythm on the drum) <b>Theme 4a &amp; 4b &amp; 18 &amp; 21</b></p>	<p><b>(SINGING)</b></p> <p>RC putting music on: ‘Oh when the saints’. ( Fats Waller/tape)</p> <p>Vocally there is call &amp; response taking place.</p> <p>Music still playing</p> <p>Music ends</p>	<p>NB ‘Call &amp; response’ meaning that the singers in the group are singing musically in the spaces between the words ( similar to gospel choirs for example)</p> <p><b>Theme 9a ‘ Complementary Narratives’</b>. It is clear in this section of dialogue that a logical sequence of thought is difficult to pick out as both Arthur &amp; Gladys appear to be following their own narratives. At times (as here) narratives may be ‘complementary’ &amp; link into each other in relation to the use of the word ‘dare’. At other times narratives may be:</p> <p><b>Theme 9b ‘Differing Narratives’</b>. Refers to the differing narratives that each individual is engaged with during a session. It is the responsibility of the therapist / group facilitator to be able to hear, honour and where possible respond to these individual narratives in appropriate ways. To perceive, intuit and/or feel the coherence within the in-coherence, or the sense within the ‘non-sense’, deepening in the process the levels (embodied) of understanding surrounding the communication ( see also Theme 10 below). Arthur also appeared throughout the session to be hearing words and responding to them, once he had thought about them, however at</p>
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	<p><b>Theme 10 &amp; 14</b>  RC: laughing  Arthur: 'Chips' <b>Theme 9b</b>  RC: 'Chess?'  MM: 'Fish &amp; Chips'  RC: 'Excellent'  Arthur: 'No, not fish &amp; chips'.  MM: 'not fish &amp; chips?'  Gladys: 'I love you.' <b>Theme 6 &amp; 9b &amp; 12</b>  SD: 'Do you? I love you too'.  <b>Theme 5b &amp; 6 &amp; 12</b>  RC: 'What have you found Gladys?'  Gladys: 'All of them'.  Arthur: ' (indistinct words then) of them'. <b>Theme 9b</b>  Gladys: 'Oyeee'  RC: (repeating Gladys's sound) 'Oyeee'. <b>Theme 11 &amp; 14</b></p> <p>RC: starts singing a music hall song 'Cheek to cheek' ( live): ' Heaven, I'm in heaven and my heart beats so that I can hardly speak and I seem to find the happiness I seek.....small gap in filming here.....  Heaven, and I love to climb a mountain and to reach the highest peak, but I don't enjoy it half as much as dancing cheek to cheek.  RC: 'Dance with me I've got my eyes about you. <b>Theme 3</b>  Gladys: 'Yes, I know'. <b>Theme 12</b>  RC: ' My heart about you, so dance with me please....see over.....</p>	<p>Gladys has picked something up off camera and I am looking at her.</p> <p>RC singing to Gladys. <b>Theme 5aa</b>  Gladys moves from her chair next to me and attempts to kiss me. <b>Theme 12.</b></p> <p>Gladys standing right next to me and looking me in the eye.</p>	<p>RC &amp; LC (singing together): ' Heaven I'm in heaven and.. <b>Theme 5a &amp; 5b</b></p> <p>RC (singing only): my heart beats so that I can hardly speak and I seem to find the happiness I seek when we're out together dancing</p>	<p>times his response was not synchronised with the current context/flow of communication and relationship with others. This apparent delay in relation to his own narrative process, could be construed as evidence of his confusion, or evidence of indifference towards others and the therapist/facilitator: it could also be seen as his taking a while to hear, process and respond to verbal communications, putting him out of relationship with the flow of the session. The work of therapist/facilitator is therefore to help the participant link into the flow of their own narratives. Ref: Widdershoven &amp; Berghmans cited in Hughes et al.</p> <p><b>Theme 10. 'As if...'</b> trying to fill in the gaps of congruence/sense where verbal or non-verbal (in this instance both verbal and non-verbal) communications are difficult to understand and/or interpret. I for example picked up on the associations made by staff ( off camera) in relation to an emerging theme of ribbons as fishing rods.... I then tried to expand &amp; develop this <b>emerging theme</b>, incorporating it into the session. (Ref: Vaihinger &amp; Ansbacher &amp; Ansbacher)</p> <p><b>Theme 11 'Repetition'</b>. I repeat what she says back to her as a way of checking out the accuracy of her communication, the words she is</p>
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11.10am	<p>SD (off camera) to Gladys: ‘What do you think of it?’ Gladys: ‘I love it’. <b>Theme 12</b> RC: ‘when we’re out together dancing, out together dancing, out together dancing, when we’re out together dancing cheek to cheek’.</p> <p>Slight break in film continuity</p> <p>RC: ‘We’ll sing it’ Arthur: ‘All the old fashioned’ RC: ‘All the old fashioned ones. <b>(Theme 11 &amp; 14)</b> I wonder, can we sing you one? Mm, can you give us a clue?’ Arthur: says something but inaudible/indistinct. <b>Theme 9b</b> RC: ‘What?’ LC: ‘You like ‘baby-face’ (referring to a song) don’t you Al?’ <b>Theme 5b &amp; Theme 10</b> Arthur: ‘Do I?’ LC &amp; others (out of shot) +RC singing: <b>Theme 5b</b> ‘Baby-face, you’ve got the cutest little baby-face, there’ll never be a one to take your place – baby-face’. <b>Theme 5a &amp; 5aa</b> Arthur: ‘Well all my wife’.</p>	<p>Slight break in film continuity</p> <p>Gladys walks past me again. <b>Theme 2a</b></p> <p>LM moving a scarf up &amp; down sat next to Arthur.</p>	<p>RC looks across at LC and by opening his eyes wide, looking at her and continuing to sing, hopes she will end the song with a ‘reprise’ on the last phrase, ‘out together dancing’.</p> <p>Slight break in film continuity</p> <p>Song/ (live) : Babyface.</p> <p><b>(SINGING)</b></p>	<p>using and my understanding of it. Question to myself: ‘am I hearing this correctly?’ Repetition is also a therapeutic technique that is used as part of the process of building a relationship. This ensures the person has been heard, communication witnessed, the meaning understood and ideally acted upon.</p> <p><b>Theme 12 ‘Emotional expression’.</b> I found these personally &amp; professionally challenging moments as they often took me by surprise. I am attempting to make a connection to Gladys by singing to her directly and she responds emotionally &amp;, spontaneously. She attempts to kiss my cheek. In hindsight, my communication towards her can be interpreted as romantic by serenading her. Supporting &amp; allowing emotional expression is an important aspect of the session. According to Ward et al, it is vital for people with dementia to express in this way and is often overlooked in care practice generally. The challenge for the therapist/facilitator is to be aware of ‘transference’ &amp; ‘counter-transference’ issues; these can be logged &amp; raised in the process of clinical supervision at a later date. Slight break in film continuity</p> <p><b>Theme 13 ‘Flow -moving-on with the session’.</b> This involves making a decision to shift the focus of attention from one person to</p>
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	<p><b>Theme 9b.</b>  LC (singing): ‘Oh my heart is jumping’.  RC (singing): ‘dah, dah, dee, dee, dee’. <b>Theme 5ac</b>  LC (singing): ‘Babyface, I’m up in heaven when I’m in your arms embrace. I didn’t need a ....? (shove?) but I just fell in love with your cutest little baby-face’.  RC: Laughing  RC: ‘Did you like that Arthur?’  <b>Theme 10</b>  Arthur: →  RC: ‘No?’  LC: ‘Oh, he’s gone off it again, he used to like it’. <b>Theme 5b</b>  RC: ‘What do you like Martin?’ <b>Theme 10 &amp; 13</b>  Martin: no response →  LC: ‘Martin, what’s your favourite song? Your song, what did you used to sing on a night when you used to go out clubbing? With Winnie’.  <b>Theme 5b &amp; 8</b></p> <p>RC: ‘Did you go dancing Martin?’  Arthur: ‘Blackpool’ <b>Theme 9b.</b>  Martin: ‘Johnson?’ →  Arthur: ‘No I didn’t that me’.  <b>Theme 9b</b>  RC: ‘Johnson?’ <b>Theme 10&amp;14</b>  Martin: ‘Al Jolson’ →  RC: ‘Al Jolson. Would you like to hear some Al Jolson, Wow, fantastic. I wish you’d said Martin. I could’ve got that</p>	<p>Arthur nods first to his left and then to his right meaning ‘no’ as I interpreted it</p> <p>Martin rubbing his nose remains silent</p> <p>Martin in silence looks at LC sat immediately to his right.</p> <p>Martin looking down at his ribbon-stick, remains silent</p> <p>RC looks directly into M’s eyes. <b>Theme 3</b></p> <p>(Martin almost in a whisper/hard to make out.) <b>Theme 10</b></p> <p>(Again very hard to make out.)</p>		<p>another i.e. from Arthur to Martin. This can be useful when an individual’s response is in the negative and it is perhaps best to leave the matter at that and not pursue it further. This can also be difficult as negative reactions often serve a purpose in letting therapist/facilitator know valuable information about the person and their immediate needs. I made a split-second decision to move on here in order to keep the flow of the session going.  (Ref: Csikszentmihalyi.)</p> <p><b>Theme 14 ‘Working with fragments’.</b> Often we find ourselves working with a fragment of a word, a memory, a feeling, a song, a story. There is a link to Theme 10 here as we try to fill in the gaps within the fragments of the communication.</p> <p><b>Theme 15 ‘Learning from mistakes/experience’.</b> One of those moments when I forgot that Martin does not know that I would like to have known sooner that he liked the music of Al Jolson. I was for that moment unintentionally verbally critical of Martin which meant that I was dis-respectful towards him verbally and in the overt way in which I said it. In hindsight, this embarrassing moment recorded on camera reminds me of the searching process I go through, in trying to</p>
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	<p>out sooner.(Theme 6 &amp; 15) I love Al Jolson, he's one of my favourites.Here we go.' →</p> <p>LC + Gladys's + others singing ( off camera):          'Oh you beautiful doll, you great big beautiful doll, let me put my arms about you, I could never live without you. Oh, you beautiful doll you great big beautiful doll, if you ever leave me then my heart will break, I wanna hug you but ...? Oh, Oh, Oh, Oh, Oh you beautiful doll Theme 5a &amp; 5aa &amp; 5b</p> <p style="text-align: center;">↓</p> <p>Music continues x 2</p> <p>Group still singing:          'Oh you beautiful doll you great big beautiful doll, let me put my arms around you I can never live without you. Oh, you beautiful doll, you great big beautiful doll: if you ever leave me how my heart will break I wanna hug you....'</p> <p style="text-align: center;"><b>Short break in filming</b></p> <p>RC:'Oh lovely,well done, well done, well done'. Theme 7          LC (To Martin): ' Did you like that Martin? You like Al Jolson don't you?'. Theme 5b          RC (to Martin): ' Cos I like Al Jolson too. Do you remember mm?</p>	<p>RC stands up moving towards CD player to switch it on.</p> <p>Gladys's moves across circle to MM, invites him to stand and dance with her in front of his chair. They swing arms side to side in time with the music. This continues till the end of the tune. Theme 4a &amp; 4b &amp; 6 &amp; 18 &amp; 12 &amp; 21</p> <p>MM and Gladys immediately in front of camera hold hands and gently rock side to side (approx. 20secs in duration). She kisses MM then sits down. Theme 4a &amp; 4b &amp; 6 &amp; 12 &amp; 18 &amp; 21</p> <p>RC leans towards Arthur Theme 10          Gladys's &amp; Martin still dancing</p> <p style="text-align: center;"><b>Short break in filming</b></p> <p>Martin's eyes appear very alert and wide.</p>	<p>RC starts playing Al Jolson /CD 'Oh you beautiful doll'.</p> <p style="text-align: center;">↓</p> <p>Music continues/trumpet solo</p> <p style="text-align: center;">Music stops</p> <p style="text-align: center;"><b>Short break in filming</b></p>	<p>find ways to make contact with people for whom it is difficult. I use both verbal and non-verbal techniques and as in this instance, this is expressed as over-bearing non-person-centred behaviour. It is important that this does not happen on a regular basis and so makes this moment a really important learning experience.</p> <p style="text-align: center;"><b>Short break in filming</b></p> <p>Theme 5aa 'Personalising songs'. (Meta-theme: 'building relationships'). This involves a technique of personalising a song that either I, or the person knows and being able to sing it especially for/to them. This I would argue is a useful technique to help engage the person in the work and the</p>
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11.15am	<p>Arthur: ‘Al Jolson?’ <b>Theme 9b</b>  RC (to Martin making eye contact) <b>Theme 3</b>: ‘Do you remember when the red red robbin? I’ll sing that for you. <b>Theme 5a &amp; 5aa</b>  RC (starts singing to Martin + others join in): ‘When the red red robin comes bob bob bobbing along – along- along – there’ll be no more .....? He comes singing this song, sweet song, wake up, wake up you sleepy head, get up, get up, get outta bed, cheer up cheer up...live, love, laugh and be happy...doo doo dee dee dee (<b>Theme 5ac</b>). There’ll be no more...till he comes singing a song, sweet song. Wake up, wake up you sleepy head, get up get up get outta bed,  Arthur: ‘I’m not in bed’ <b>Theme 9b</b>  RC &amp; others: ‘cheer up, cheer up, live, laugh, love and be happy... lah, lah, lah etc.....(till the end of the song)...live, love, laugh and be happy ( song fades out)’.</p> <p>LC: ‘ ...your ribbon, your ribbon Valerie’.</p> <p>Arthur: ‘ says something indistinct’. <b>Theme 9b</b></p> <p>RC ( to Arthur): ‘ White man is coming? (<b>Theme 10 &amp; 14</b>) Mmm, white man is coming. Thank you’. <b>Theme 7</b> (Change</p>	<p>Shaking hands with Martin. <b>Theme 1d</b></p> <p>Martin starts mouthing the song to me. Significant moment in terms of Martin’s very limited capacity for speech. <b>Theme 5a &amp; 5ab &amp; 6</b></p> <p>Martin seen moving his ribbon stick up &amp; down. <b>Theme 4a &amp; 4b &amp; 18 &amp; 19 &amp; 21</b></p> <p>Group start putting their ribbon sticks on the floor in centre of circle to make a display of the props.</p>	<p>Singing of song: ‘ When the red red robbin etc’.</p> <p>End of song</p> <p><b>(TALKING)</b></p>	<p>therapeutic process. It also helps build relationships between people through music and song. If people with dementia have difficulty with word finding, it is in my experience, often possible for the person to remember not just a few but possibly all the words of a song. ( see below / <b>theme 5ab</b>)</p> <p><b>Theme 5ab ‘Importance of song/singing in increasing well-being’.</b> An important example of where a person with very little, if no speech, is able to hear and recognise the tune, remember and mouth many of the words of the song. This is significant I would argue in the context of the person’s life and ability to communicate verbally and in the sensual (sensory) nature (sound) of the experience. It is giving back to the person ‘remembrance’ of a song that they liked and learnt when they were younger in age, possibly when the song first came out in the 1950’s. The fact that it is remembered in this context may also be important because others ( including staff), as well as Martin, can see, recognise and validate its importance. It may also contribute as in this instance to an increase in observed well-being as reported in the accompanying DCM scores ( further important independent evidence of the value of song/singing in this context).</p> <p><b>Theme 5ac ‘Singing without the</b></p>
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	<p>of focus to Martin). <b>Theme 10 &amp; 13</b></p> <p>RC: ( to Martin) ‘ Martin, what do you see down there (Martin looking at floor display of ribbons &amp; instruments) Does it remind you of anything? Colour ribbons &amp; instruments.’</p> <p>Arthur: ‘ Colour, ribbons’.</p> <p>RC: (to Arthur) ‘Yeah, those colourful ribbons there (pointing at floor →) I think that’s what we call them’.</p> <p>Arthur: ‘Coloured’. <b>Theme 9b</b></p> <p>RC: ‘ Mmmm’.</p> <p>Arthur: ‘ Coloured’.</p> <p>RC: ‘ Colourful, yes.’ <b>Theme 10 &amp; 14</b></p> <p>Arthur: says something very indistinct.</p> <p>RC (to Arthur): ‘Coloured, Scotland. <b>Theme 10 &amp; 11</b></p> <p>Mmm, have you been to Scotland?’</p> <p>Arthur: ‘Every year’.</p> <p>RC: ‘ Mmm, where have you been, do you remember?’</p> <p>Arthur: ‘ Scotland.’</p> <p>RC: ‘ Thank you. (change of focus across the group <b>Theme 13</b> ) Do you like that shakers? ( sound →)</p> <p>Yeah, Gladys (to Gladys) do you like that down here what we’ve done, made a little display? You don’t have to’.</p> <p><b>Theme 8</b></p> <p>Gladys: ‘ Mmm, (looking up at me from across the circle).’</p>	<p>Martin nods head up and down.</p> <p>RC pointing at floor so that Arthur may be able to see the display better.</p> <p>Arthur head bowed.</p>	<p><b>words’</b>. On occasion it may not be possible to remember the words of a song especially when others in a group can’t. In this case it is important to keep the rhythm and pulse of the song going by humming or using ‘lah lah’ and as in this case ‘doo, doo, dee, dee’ etc.; not for too long but just long enough to enable others to join in this process and for the experience to remain enjoyable.</p>
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11.20am	<p>RC: ‘ Oh well, I think we’re coming to the end of our time together. Let’s hold hands, let’s hold hands ( Theme 11)→ Thank you very much for coming. Theme 7</p> <p>LM:(to Arthur) Can I hold your hand? Theme 8</p> <p>Arthur: ‘ Hold my hand?’ →</p> <p>RC: ‘ Thank you very much for coming, thank you very much for coming this morning.’ Theme 7 &amp; 11</p> <p>Arthur: (starts singing spontaneously) → ‘ Angels in the heights adore him’. (pause in singing) → Theme 5a &amp; 5ab &amp; 9b &amp; 12 &amp; 16</p> <p>RC + LC + others: ( keep on singing) ‘ La, La (Theme 5ac &amp; 5b),..we behold him face to face. Sun and moon bow down before him, La, La, La...Praise him, Praise him, Praise him, Praise him, Praise the everlasting lord’.→</p> <p>LC: ‘ Oh,that was lovely Arthur’. Theme 5b &amp; 7</p> <p>MM: ‘ Praise the everlasting what Arthur?’ Theme 5b</p> <p>Arthur: ‘Prince’. Theme 9b</p> <p>MM: ‘Prince’.</p> <p>LC: ‘ Prince’ Theme 5b</p> <p>Gladys: ‘ Prince’. Theme 5b</p> <p>RC: ‘Ah’.</p> <p>MM: ‘It varies though on, on its verse it changes, doesn’t it? It’s a King on one, a Prince on</p>	<p>Group holding hands together.</p> <p>Arthur places his hand in Lynn’s. She strokes his hand with her thumb. Theme 1c</p> <p>↓</p> <p>(HYMNS &amp; SINGING)</p>	<p>Sound of shakers Theme 20</p> <p>Arthur starts singing hymn. Theme 6</p> <p>Arthur pauses singing.</p> <p>Group keep on singing what Arthur has started.</p> <p>Group singing ends</p>	<p>Theme 16 ‘ Spontaneous expression’. Quite often in a session an individual may choose to sing as in this example, to say a few words or to dance or move quite unexpectedly or spontaneously. I would argue that this is an example of the person being touched emotionally (also Theme 12) and called in some way to offer this contribution spontaneously while participating in the group. This is an example of the special, often unscripted &amp; unplanned nature of this work and approach. There are opportunities &amp; moments during a session for something remarkable and memorable to happen. I would argue that this is evidence of it. Also, it is about the importance of this approach in allowing expression of that for which there is no other way for it to be expressed. The arts are I would argue unique in enabling this creative expression. Could this moment also be related to the physical touch he is receiving at this time from LM? The touch is possibly helping Arthur feel valued and valuable enough, at this time, for him to be able to express himself in this profoundly personal way.</p>

	<p>another one’.</p> <p>Arthur: ‘ God said please do not eat apples’*. <b>Theme 6 &amp; 9b &amp; 16</b></p> <p>Gladys: ‘Grandad’. <b>Theme 6&amp;9b</b></p> <p>MM: ‘ Apples Arthur?’</p> <p>Gladys: ‘Yes, I don’t want them’ <b>Theme 9b.</b></p> <p>MM: ( still to Arthur) ‘ What reminded you of an apple?’</p> <p>Arthur: ‘ What reminds me of an apple? An apple, is an apple, is an apple’.</p> <p>MM: ‘ Oh right. I think I saw you looking down there at that red shape and that reminded you of an apple.’ <b>Theme 10 &amp; 11.</b></p> <p>Arthur: ‘ She said, my dear child, there is no scientific proof of a God’. <b>Theme 9b &amp; 16 &amp; 17.</b></p> <p>RC: (repeats) ‘ She said my dear child there is no scientific proof of a God?’ <b>Theme 11.</b></p> <p>Arthur: ( says quietly head bowed) ‘There is scientific proof’ (<b>Theme 17</b>)</p> <p>RC: ‘ Mmm’</p> <p>Pause (<b>Theme 13</b>)</p> <p>RC: ‘ Well, thank you for that Arthur, thank you very much ( Theme 7) for that. Well I wonder if there is anything else we can finish with, we can sing all together?’ <b>Theme 13</b></p> <p><b>Short break in filming</b></p> <p>RC + LC &amp; others: (singing) <b>Theme 5ab &amp; 5b</b> ‘ Again, don’t</p>	<p>LM still stroking Arthur’s hand</p> <p><b>Short break in filming</b></p> <p>Group hold hands around the circle</p>	<p><b>Short break in filming</b></p> <p>Group start singing ex-second world</p>	<p>* Very interesting reference by Arthur to ‘Adam &amp; Eve’ story &amp; possibly the concept of ‘Paradise’ within the Christian tradition. I assume therefore that Christianity is of some, if not great importance to him.</p> <p><b>Theme 17 ‘Working with contradiction’.</b> Sometimes a person is contradictory and it is necessary for the group facilitator to try and make sense of the non-sense (<b>Theme 10</b>) or in this instance the contradiction. In hindsight, Arthur is likely to have a strong link to Christianity having sung the first words of a hymn earlier and here he may have realised that he was contradicting himself by saying, ‘there is no scientific proof of a God’ when in fact he knows that there is! This is potentially sophisticated reasoning for a person with a dementing illness in the moderate to late stages. (<b>Meta theme – importance of religion/spiritual practice.</b>)</p> <p><b>Short break in filming</b></p> <p><b>Theme 18 Embodied connections: ‘Physical Mobility &amp; Exercise’.</b> It</p>
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11.25am	<p>know where, don't know when but I know we'll meet again some sunny day. Keep smiling through just like you always do till the....dark clouds drive the (RC sings: 'blue clouds') far away. And won't you please say hello to the folks that I know tell them I won't be long, I'll be happy to know as you saw me go –I'll be singing this song. We'll meet again don't know where don't know when but I know we'll meet again some sunny day.'</p> <p>RC: 'Ah, lovely, thank you very much' <b>Theme 7</b> (spontaneous clapping → Martin seen clapping enthusiastically and looking at RC)</p> <p>RC: (To Martin): 'Thank you for coming Martin, thank you very much for coming today. (<b>Theme 7</b>) Thank you very much. (to everybody in group) I won't be coming next week.'</p> <p>RC: 'Thank you for coming Valerie. Thank you for coming today, thanks very much.' <b>Theme 7</b></p> <p>RC: 'OK' →</p> <p>LC: (to Martin) 'Do you want to go back in the big room?'</p>	<p>and moving side to side. <b>Theme 4b &amp; 5a &amp; 18 &amp; 21</b></p> <p>MM seen holding hands with Gladys while still sitting in his chair and rocking her hands side to side. <b>Theme 1e &amp; 4b &amp; 6 &amp; 18 &amp; 19 &amp; 21</b></p> <p>Martin seen mouthing the words of the song again.</p> <p>Group clap spontaneously. <b>Theme 7 &amp; 16</b></p> <p>I lean towards Arthur on my left. I move across to Valerie to sit in vacant chair on her right. I hold and shake her hand. <b>Theme 1e &amp; 7</b></p> <p>MM seen holding Gladys's hand and escorting her out of the room to the adjacent main lounge area. <b>Theme 5b</b></p>	<p>war military song: 'We'll meet again'.</p> <p>↓</p> <p>End of song.</p> <p><b>SCARF</b></p>	<p>is evident throughout the session that physical mobility and exercise play a very important part. They are part of the embodied processes in the session and are of special benefit to people with neurological problems such as in dementia. Specifically there was considerable focus placed on use of the hands and feet in the session as mobility was restricted due to vulnerability and frailty of participants.</p> <p><b>Theme 19 'Use of props'</b>. Props play an important role in the session and they are used in a variety of ways to encourage people to participate, including staff. To enable particular movement qualities especially where scarves are used and during this session an 'elastic band' that connected the whole group in the circle was of particular importance. Very frail people such as Gladys, who liked to move about the room independently, can hold onto the elastic and feel in their bodies the movements of the elastic as everybody holds on and tries to move it in their own way. Sometimes this can be choreographed, more often it happens spontaneously.</p> <p><b>Theme 20 'Use of instruments'</b>. Instruments are very important during a session, as however frail, almost everyone is able to choose, hold onto and play an instrument at some point. There is no right and/or wrong way to play them and</p>
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<p>11.30am</p>	<p>(Theme 8) Oh you want a scarf, here you are then, you hold the scarf’.</p> <p>LC: ‘Here you are Valerie’.</p> <p><b>End of session</b></p> <p>Gladys: addresses someone in a chair in front of her: ‘ Hello darling’. Theme 9b DB (DCM mapper): (to Gladys) ‘Hello sweetheart’. Gladys: ‘Nanny, Nanny’ Theme 6 &amp; 9b Arthur: ‘Grandfather’. Theme 6 &amp; 9a &amp; 9b Gladys: ‘in the make?’ Arthur: ‘ How old is my grandmother?’ Gladys: ‘Granny, Granny’. <b>End of filming</b></p>	<p>Martin points at something on the floor. LC interprets this as meaning a scarf and pulls a black one out from under where she was sitting. Starts dancing with it. Theme 4b &amp; 5b &amp; 18 &amp; 19 &amp; 21 LC gives Valerie a yellow scarf. Theme 5b &amp; 19</p> <p>Arthur &amp; Valerie seen holding and dancing with scarves, up and down with LC. Theme 4b &amp; 13 &amp; 19 &amp; 21</p> <p>LC seen dancing standing up with Martin then leads him out of the room. (Theme 5b &amp; 18 &amp; 19 &amp; 21) LM now seen standing with Arthur taking him by the arm and leading him out of the room. Theme 5b</p> <p><b>End of session</b></p> <p>Cut to the main lounge where a middle-aged man is sat in front of a person in a wheelchair. There is a yellow Labrador dog that the man is holding close to his chair on a short leash. Gladys is seen walking around the room. Theme 2a</p> <p>Gladys sits in armchair next to DB on her right with Arthur sat on her left also in an armchair. Gladys no sooner sat down than she starts walking around the room again. Theme 2a</p> <p><b>End of filming</b></p>	<p>RC puts on more music to close session/ jazz. Theme 4a</p> <p><b>End of session</b></p> <p><b>AFTER SESSION</b></p> <p><b>N.B. Themes in red, here in italics after 11.30am not counted in Table 5 analysis.</b></p> <p><b>End of filming</b></p>	<p>the focus is both on the sensual qualities of the sounds produced and that participants are able to use them in a creative and expressive way. The rhythmic movement aspects of keeping a rhythm going are also valuable and so this theme also links into Theme 4b.</p> <p><b>Theme 21 ‘ Use of Dancing’.</b> This is an important element of the session, however the amount of dancing in any one session is not pre-determined; it varies and depends on a number of factors, including familiarity with the medium, which tends to increase over time as the number and frequency of sessions increase. It also depends on the skill levels and confidence of therapist/facilitator using the medium. The confidence of participants to express themselves through dance is, in my experience likely to increase especially if they have had previous experience of the medium. The intention is to support, encourage and develop the use of small movement sequences, motifs and phrases that then evolve or transform into a dance. Sometimes an individual dances spontaneously, either in their chair or standing-up, or they might start in their chair and continue while standing-up.(Refs: Amans, Coaten, Donald, Gibson, Palo-Bengtsson, Kasayka).</p> <p><b>End of filming</b></p>
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## Appendix B: Differentiating the VTR Transcript Themes & Frequency of Occurrence in Session

		Text in this column is slightly different to that in original		
Theme No:	Theme Title:	Details:	Link to other themes:	Frequency of occurrence x
5b	<b>‘Importance of staff contribution to session’</b>	Contributions from all participating staff are important in giving staff the confidence to value their own stories, life experience and to help build better relationships with those in their care ( see meta-theme building relationships). Also contributes to development of their own skills ( staff development/see meta-theme) as group facilitators and that they learn a lot more about their patients/residents than they might otherwise in the care home or ward context alone ( Ref: Ward et al )	Nos. 1a & 1c & 1e & 2b & 3 & 4a & 4b & 5a & 5aa & 5ab & 5ac & 6 & 7 & 8 & 10 & 12 & 13 & 14 & 16 & 17 & 18 & 19 & 20 & 21	30
18	<b>‘Embodied Connections: physical mobility &amp; exercise’</b>	It is evident throughout the session that physical mobility and exercise play a very important part. They represent another aspect of the embodied processes in the session and are of special benefit to people with neurological problems such as in dementia. Specifically, a focus placed on use of the hands and feet and torso in the session as mobility was restricted due to vulnerability and frailty of participants. Health & Safety related issues are also important in not tiring out participants.	Nos. 1a & 1c & 1d & 1e & 2a & 2aa & 2b & 3 & 4a & 4b & 5a & 5aa & 5ab & 5ac & 6 & 7 & 8 & 9a & 9b & 10 & 11 & 12 & 14 & 16 & 17 & 19 & 20 & 21	24
9b	<b>‘Differing Narratives’</b>	This describes an important phenomenon referring to the differing or individual narratives that people with dementia appear to be following or engaged with in a session. These narratives appear to be unique to the individual and as evidenced throughout the session, are expressed at different times. I would argue these narratives are not unique to a session of this type, as evidenced by the fact that they seemed to continue	Nos. 1d & 1e & 2a & 2aa & 4a & 4b & 5a & 5aa & 5ab & 5ac & 5b & 6 & 7 & 8 & 10 & 11 & 12 & 14 & 15 & 16 & 17 & 18 & 19 & 20 & 21	22

		once the session had finished. They also appear to be closely influenced by the narratives of others as referred to in Theme 9a above and they are important to the person in terms of 'meaning-making' – making sense of the world in spite of the confusion ( Widdershoven & Berghmans cited in Hughes et al.). This theme also links strongly to 10 below.		
<b>4b</b>	<b>'Importance of rhythmic movement'</b>	Strong links to the work of early DMT pioneer (Chace) linking rhythmic movement (stamping feet/moving arms in unison) and music as a unifying factor in a group setting. Also as an embodied practice it is very relevant for those with cognitive & neurological difficulties helping them experience more embodied contact with themselves. Also important as a failure free activity with no right/or wrong and strong links to Themes 18, 19 & 21 in particular.	Nos 1e & 3 & 4a & 5a & 6 & 8 & 12 & 16 & 18 & 19 & 20 & 21	<b>=22</b>
<b>7</b>	<b>'Giving Praise'</b>	A way of validating persons in the group involving witnessing, recognising and valuing the verbal and non-verbal communications and behaviour they make (including staff) with important links to the meta-themes (building relationships, maintaining social role functioning & person-centred care).	Nos. 1e & 3 & 6 & 12 & 14 & 16 & 18 & 19 & 20 & 21	<b>20</b>
<b>21</b>	<b>'Use of Dancing'</b>	This is a very important element of the session, however the amount of dancing is not pre-determined; it varies and depends on a number of factors, including familiarity with the medium, which tends to increase over time as the number and frequency of sessions increases. It also depends on the skill levels and confidence of therapist/facilitator using the medium. The intention is to support, encourage and develop the use of small movement sequences, motifs and phrases that then may evolve or transform into a dance. Sometimes an individual dances spontaneously, either in their chair or standing-up, or they might start in their	Nos. 1e & 2a & 2aa & 2b & 3 & 4a & 4b & 5a & 5aa & 5ab & 5ac & 6 & 7 & 8 & 9a & 9b & 10 & 11 & 12 & 13 & 14 & 16 & 17 & 18 & 19 & 20	<b>19</b>



		chair and continue while standing-up. Strong links to meta-theme of 'Increasing well-being' & 'improving mobility'. <b>Themes 4a &amp; 4b &amp; 18</b> (Refs: Amans, Coaten, Donald, Gibson, Palo-Bengtsson, Kasayka).		
<b>10</b>	<b>'As if.....'</b>	As therapist/facilitator we are constantly attempting to make sense of people's narratives (Theme 9b) their wants and needs, thoughts and feelings. If we listen to people with dementia 'as if' what they are saying, their 'fictions' have meaning, in spite of any factual inaccuracies, then outcomes for the person are likely, in my experience, to be more positive and meaningful than would otherwise be the case.( Vaihinger /Ansbacher & Ansbacher). In other words we try and fill in the gaps of our 'not knowing', we make sense out of 'non-sense', we make difference and diversity in our communications and relationships the norm rather than the exception. This also means the onus is on the therapist/facilitator at all times to listen to illicit the intention and meaning underlying the communication.	Nos.1a & 1c &1d &1e &2a &2aa & 3 &4b & 5a & 5aa & 5ab & 5Ac & 6 & 9b & 12 & 14 & 16 & 17 & 18 & 21	<b>18</b>
<b>4a</b>	<b>'Importance of Music'</b>	Use of a mixture of live & recorded music very important in this context. (Refs: Bright,1987). The appreciation and use of music appears to act as an important medium of communication especially for people who may be severely affected by dementia syndrome. Strong links to other themes. Links also to meta-themes of building relationships/social role functioning.	Nos. 3 & 4b & 5a & 5b & 12 & 13 &14 &16 & 18 & 19 & 20 & 21	<b>17</b>
<b>6</b>	<b>'Maintaining identity &amp; awareness of symbol formation'</b>	An acknowledgement that for people with dementia suffering many losses in relation to activities of everyday living and neurological functioning including memory, questions around 'identity' and place in society and the world, are of increasing importance. Often in clinical practice these important existential	Nos. 1a & 1c & 1e & 2a & 2aa & 3 & 4a & 4b & 5a &5aa & 5ab & 5ac & 7 & 8 & 9a & 9b & 10 &11 & 12 & 13 &	<b>14</b>

		questions are present either consciously and/or unconsciously in everyday communications and behaviour. People need reminding of who they are. As a psychotherapist I am trained to be aware of and work psychotherapeutically with these questions and behaviour as they manifest in a group and one-to-one setting. (Ref: Bowlby & Attachment Theory)	14 & 16 & 18 & 19 & 20 & 21	
<b>14</b>	<b>‘Working with fragments’</b>	Often we as therapist/facilitator find ourselves working with, or reflecting on a fragment of a word, a feeling, a memory, a song, a dance or story in order to help give back to the person something that is of importance to them at that moment. This can involve an attempt to ‘hold’ or ‘contain’ the space, for an individual or group, in a psychological sense, in order that something creative and/or expressive can happen. This links to a meta-theme of ‘ Supporting Person-Centred Care’. Also with fragments, metaphorically we might want to help create a ‘mosaic’, or with a ‘thread’ we might want to weave a new garment with it; something not yet created. The acceptance remains on the part of the therapist/facilitator, that in spite of great confusion, the creative act remains a viable and sometimes vital proposition for people with the condition.	Nos. 2a & 2aa & 3 & 4a & 4b & 5a & 5aa & 5ab & 5ac & 6 & 7 & 8 & 9b & 12 & 14 & 16 & 18 & 19 & 20 & 21	<b>13</b>
<b>5a</b>	<b>‘Importance of singing’</b>	Singing of particular importance in the session with strong links to emotional expression, a failure free activity and contributes to increasing well-being ( see meta-themes) and self-esteem (Ref: McMorland).	Nos. 4a & 6 & 8 & 12 & 13 & 14 & 5aa & 5ab & 5ac & 16 & 18 & 20 & 21	<b>12</b>
<b>19</b>	<b>‘Use of props’</b>	Props play an important role in the session as they are used in a variety of ways to encourage people to participate, including staff. Scarves for example enable particular movement qualities, ‘light and floating’ and during the session an ‘elastic band’ was used to connect the whole group in the circle. Very frail people such as Grace, who liked to move about the room	Nos, 2a & 2aa & 2b & 3 & 4a & 4b & 5a & 5aa & 5ab & 5ac & 6 & 7 & 8 & 9a & 9b & 10 & 11 & 12 & 14 & 16 & 18 & 20 & 21	<b>=10</b>

		independently, can hold onto the elastic and I would argue feel in their bodies the movements of the elastic as everybody holds on and tries to move it in their own way. Sometimes this can be choreographed, more often it happens spontaneously. Props used: Pink elasticated band / ribbons on sticks and colourful schiffon & silk scarves.		
11	<b>‘Repetition’</b>	Repetition is an important therapeutic technique as a way of checking out the accuracy of a person’s communications whether verbal and/or non-verbal. It is also part of the process of building a relationship with someone. This ensures the person has been heard, communication witnessed, the meaning understood and if necessary the communication acted upon.	Nos. all	<b>=10</b>
8	<b>‘Giving/enabling choice’</b>	It is very important to respect the decisions and choices participants make in relation to participating in the session, in activities, in communications etc. Maintaining this particular aspect of the session is I would argue a necessity, especially in relation to respecting the rights of very frail and vulnerable people to have their wishes and desires respected and carried out at all times. (Links to meta-theme of respecting personhood within framework of person-centred care.)	Nos.1a & 1c & 2a & 2aa & 2b & 3 & 4a & 4b & 5a & 6 &12 & 14 & 15 & 16 &17 &18 & 19 & 20 & 21	<b>=10</b>
12	<b>‘Emotional Expression’</b>	Supporting, allowing, enabling and facilitating emotional expression is an important aspect of the session. According to Ward et al, it is vital for people with dementia to be able to express themselves emotionally and is an aspect often overlooked in the care practices they studied. The challenge for the therapist is also to be aware of the ‘transference’ and the counter-transference’ issues and to be able to work through them with the help of a skilled clinical supervisor.	Nos. 3 & 5a & 6 & 8 & 9b &14 &16 &18 & 20 &21	<b>9</b>
13	<b>‘Flow – moving on with</b>	A useful technique to enable the flow of a session to	Nos. 2a & 2aa & 6	

	<b>the session'</b>	continue without focusing attention on any one individual or exercise for an overly long period. An assessment is made at what point to move on, ideally without causing offence or annoyance to any participant and without missing out on a valuable comment, or contribution from a person. (Ref: Csikszentmihalyi).	& 8 & 9b & 12 & 14 & 16 & 17 & 18 & 21	<b>8</b>
<b>3</b>	<b>Embodied connections: - eye contact'</b>	Very important 'embodied' aspect of session & of particular relevance to meta-theme ( see meta-themes) of building relationships between all involved in the session.	Nos.1c & 10 & 12 & 16 & 21	<b>=6</b>
<b>2a</b>	<b>'Inclusion/Exclusion'</b>	Facilitator/therapist needs to be able to support person's need to walk around/move freely in the room. Expressing their need in this embodied way. Strong link to Theme 8.	Nos.2aa & 8	<b>=6</b>
<b>5aa</b>	<b>'Personalising Songs'</b>	This involves a technique of personalising a song that either I, or the person knows and being able to sing it especially for/to them. This I would argue is a useful technique to help engage the person in the work and the therapeutic process. It also helps build relationships between people through music and song. If people with dementia have difficulty with word finding, it is in my experience, often possible for the person to remember not just a few but possibly all the words of a song. Meta theme 'Building Relationships'.	Nos. 4a & 6 & 8 & 12 & 13 & 14 & 5a & 5ab & 5ac & 16 & 18 & 20 & 21	<b>5</b>
<b>16</b>	<b>'Spontaneous Expression'</b>	Quite often in a session an individual may choose to sing as in this example, to say a few words, dance or move quite unexpectedly or spontaneously. I would argue that this is also an example of the person being touched emotionally ( see also Theme 12) and needing to offer their contribution spontaneously while participating in the group. This describes the often unscripted & unplanned nature of this work and approach. There are opportunities & moments during a	Nos. 1a & 1d & 1e & 2a & 2aa & 3 & 4a & 4b & 5a & 5aa & 5ab & 5Ac & 6 & 7 & 8 & 9a & 9b & 10 & 11 & 12 & 13 & 14 & 15 & 17 & 18 & 19 & 20 & 21	<b>=4</b>

		session for something remarkable and memorable to happen. I would argue that this example is evidence of it. Also, it is about the importance of this approach in allowing expression of that for which there is no other way for it to be expressed. The arts are I would argue unique in enabling this creative expression. Could this moment also be related to the physical touch he is receiving at this time from Lynn? The touch is possibly helping Albert feel valued and valuable enough, at this time, for him to be able to express himself in this way.		
<b>1c</b>	<b>Embodied Connections: - Height levels</b>	Kneeling or squatting down to reach eye level of person /supporting communication & relationship.	Nos. 12	<b>=4</b>
<b>9a</b>	<b>‘Complementary Narratives’</b>	This describes a phenomenon where individual’s each with their own tangible, coherent and sometimes symbolic narrative or frame of reference, become linked into and influenced by someone else’s. There were numerous occasions during the session when this appeared to be taking place. There are important links between this theme and 9b & 10 below.	Nos. 1d & 1e & 4a & 4b & 5a & 5aa & 5ab & 5ac & 5b & 6 & 7 & 8 & 10 & 11 & 12 & 14 & 15 & 16 & 17 & 18 & 19 & 20 & 21	<b>=3</b>
<b>5ab</b>	<b>‘Importance of song/singing in increasing well-being’</b>	Refers to where a person with very little, if no speech, is able to hear and recognise the tune, remember and mouth many of the words of the song. This is significant I would argue in the context of the person’s life and ability to communicate verbally and in the sensual (sensory) nature, the sound of the experience itself. It is giving back to the person ‘remembrance’ of a song that they liked and learnt when they were younger in age, possibly when the song first came out. The fact that it is re-remembered in this context may also be important because others ( including staff), as well as Martin, can see, recognise and validate its importance. It may also contribute as in this instance to an increase in observed well-being as reported in the	Nos. 4a & 6 & 8 & 12 & 13 & 14 & 5a & 5aa & 5ac & 16 & 18 & 20 & 21	<b>=3</b>

		accompanying DCM scores ( further important independent evidence of the value of song/singing in this context		
<b>5ac</b>	<b>‘Singing without the words’</b>	On occasion it may not be possible to remember the words of a song especially when others in a group can’t. In this case it is important to keep the rhythm and pulse of the song going by humming or using ‘lah lah’ and as in this case ‘doo, doo, dee, dee’ etc.; not for too long but just long enough to enable others to join in this process and for the experience to remain enjoyable. Sometimes all that is needed is for the group to get to the end of the song and for the experience to feel valuable in and of itself.	Nos. 4a & 6 & 8 & 12 & 13 & 14 & 5a & 5aa & 5ab & 16 & 18 & 20 & 21	<b>=3</b>
<b>2b</b>	<b>‘Health &amp; Safety’</b>	Very important to be aware of and anticipatory towards health & safety issues at all times e.g. any objects that may cause a fall (e.g. scarves/elastic/ribbon sticks), or person become tired out through exposure to any activity for too long. Requires constant monitoring.	Nos. (all)	<b>=3</b>
<b>1e</b>	<b>‘Embodied Connections’ - Hand Holding</b>	Making contact non-verbally by holding participant’s hand in conscious and sensitive way.	Nos. 6 & 10 & 12 & 16 & 18 & 21	<b>=3</b>
<b>20</b>	<b>‘Use of instruments’</b>	Instruments are very important during a session, as however frail, almost everyone is able to choose, hold onto and play an instrument at some point. There is no right and/or wrong way to play them and the focus is both on the sensual qualities of the sounds produced and that participants are able to use them in a creative and expressive way. The rhythmic movement aspects of keeping a rhythm going are also valuable and so this theme also links into <b>Themes 4a &amp; 4b</b> . Musical instruments used ( tambourines, marracas, shakers & drum)	Nos. 2a & 2aa & 2b & 3 & 4a & 4b & 5a & 5aa & 5ab & 5ac & 6 & 7 & 8 & 9a & 9b & 10 & 11 & 12 & 14 & 16 & 18 & 21	<b>=2</b>
<b>17</b>	<b>‘ Working with contradiction’</b>	Sometimes a person is contradictory and it is necessary for the therapist/facilitator to try and make	Nos. 1a & & 1d & 1e & 2a & 2aa & 3	

		sense of the erstwhile 'non-sense' ( <b>Theme 10</b> ) or in this instance the contradiction. In hindsight, Arthur is likely to have a strong link to Christianity having sung the first words of a hymn earlier and here he may have realised that he was contradicting himself by saying, 'there is no scientific proof of a God' when in fact he knows that there is! This is potentially sophisticated reasoning for a person with a dementing illness in the moderate to late stages.	& 4a & 4b & 5a & 5aa & 5ab & 5ac & 6 & 7 & 8 & 9a & 9b & 10 & 12 & 14 & 16 & 18 & 19 & 20 & 21	=2
<b>1d</b>	<b>Embodied Connections: - Body Memory</b>	Reference to a body memory of participant & I having met at previous session the week before? Expressed through the physicality of person shaking my hand for a considerable period of time.	Nos. 1c & 1e	=2
<b>15</b>	<b>'Learning from mistakes'</b>	At this point in the session I was very excited by having made contact with Martin in relation to the music of Al Jolson. 'Wow, fantastic. I wish you'd said Martin. I could've got that out sooner', referring to the music of Al Jolson which I had available in my case. In this instance I was verbally and unnecessarily critical of him which was unprofessional of me as therapist/facilitator and training programme director at that time. This proved to be an important learning moment for me.	Nos. All	=1
<b>2aa</b>	<b>'Walking around room'</b>	Participant (Gladys) walks around the room fairly constantly during session & afterwards and on one occasion walks down an adjacent corridor.	Nos. 2a & 8	=1
<b>1a</b>	<b>Embodiment well supported</b>	Staff participant allowing someone to sit where they want to. Strong link also to Theme 8	Nos.8	=1
<b>1b</b>	<b>'Embodiment not well supported'</b>	Staff participant(s) moving person in their chair without preparatory warning or communication.		=1
NB the complexity of links, 'web of connections' between the different themes makes it hard to differentiate them.				

# APPENDIX C

# DEMENTIA CARE MAPPING (7<sup>th</sup> EDITION) RAW DATA SCORES SHEET

DATE: APRIL 2002

TIME PERIOD: 09.40-11.55hrs

PLACE: Ward

PARTICIPANTS: 4

STAFF: 5

OBSERVER: DB

Participant Name	Time	09:40	09:45	09:50	09:55	10:00	10:05	10:10	10:15	10:20	10:25	10:30	10:35	10:40	10:45	10:50	10:55	11:00	11:05	11:10	11:15	11:20	11:25	11:30	11:35	11:40	11:45	11:50	11:55	12:00
Martin (Sheet3)	BCC	B	B	B	B	B	B	X	B	B		E	E	E	E	E	J	E	E	E	E	E	J	X	B	B	B	B	B	
	WIB	+1	+1	+1	+1	+1	+1		+1	+1		+3	+5	+5	+5	+5	+5	+5	+5	+5	+3	+3	+5		+1		+3	+1	+1	
Valerie (Sheet4)	BCC	B	X	X	B	B	B	B	B	B		E	B	E	E	E	J	E	E	B	B	E	J	B	A	X	B	B	B	
	WIB	+3			+1	+1	+1	+1	+1	+1		+1	+3	+1	+5	+5	+3	+5	+1	+3	+3	+3	+5	+3	+3		+3	+1	+1	
Arthur (Sheet5)	BCC	A	A	A	A	A	A	M	X	X		A	B	E	B	A	A	A	A	A	B	E	E	A	A	A	X	B	A	
	WIB	+1	+1	+1	+1	+1	+1	+1				+1	+1	+1	+1	+1	+3	+1	+1	+1	+3	+3	+1	+1	+1			+1	+1	
Gladys (Sheet6)	BCC	K	K	K	K	K	K	K	K	K		X	A	E	K	E	E	A	A	E	S	E	X	K	K	A	K	K	K	
	WIB	+3	+3	+3	+3	+3	+3	+1	+1	+1			+1	+3	+3	+5	+1	+3	+5	+5	+1	+5		+3	+3	+3	+3	+3	+3	
(Sheet7)	BCC																													
	WIB																													
(Sheet8)	BCC																													
	WIB																													
(Sheet9)	BCC																													
	WIB																													
(Sheet10)	BCC																													
	WIB																													

WARM-UP

DEVELOPMENT

CLOSURE

COPY OF  
OBSERVER'S  
NOTES →

SINGING  
RUBBING HANDS  
CLAPPING  
DANCING IN O

MARACCAS  
MUSICAL INSTRUMENT  
FEET-TAPPING SCOTTISH  
SINGING + RIBBONS  
+ SINGING

SINGING  
TALKING  
HYMNS + 'WE'LL MEET AGAIN'  
SCARF



## APPENDIX D

### *On-going evaluation*

#### **Part 1**

Please think about our work together last week, both in the training day and during the session you participated in and write your answer below to the following general question: **What would you see yourself doing differently as a result of what we have done ?**

#### **Session evaluation**

Please complete each of the following sentences:

During the session I saw.....

During the session I felt...

During the session I imagined.....

#### **Effects on clients**

Has the training programme and its application in the sessions so far contributed to supporting clients in : please place a score above the line, opposite the question e.g. If your answer is: Very helpful 5, Helpful 4, No difference 3, Unhelpful 2, Confusing 1.

Maintaining / developing identity and personal relationships ? .....

Maintaining contacts in isolating situations ? .....

Promoting communications where difficult ? .....

Maintaining / improving mobility ? .....

Others:

please write your own in the space provided and score appropriately

.....

## Part 2

Here are some possible goals to help you become more effective at the provision of activities for your clients / residents. They are taken from Scottish Vocational Care Qualifications at Levels 2, 3 & 4 and will be similar to the English NVQ's. Please use this list as reminders to help you complete your own list of personal / professional goals for completion at the bottom of the page:

- 1) Prepare implement and evaluate agreed therapeutic group activities with other members of the care team.
- 2) Prepare and provide agreed developmental activities for clients.
- 3) Prepare and provide equipment ( e.g. props and music) and materials for use in development programmes.
- 4) Enable clients to participate in recreation and leisure activities.
- 5) Prepare and support clients through therapeutic group activities.
- 6) Contribute to the development of a culture in which people are . respected and valued as individuals
- 7) Structure learning opportunities with individuals.
- 8) Promote effective communication and relationships.

Please write your own personal goals for the programme here...they may relate to the above or not. The above are meant as a guide to the field in which we are working...the effective provision and implementation of high quality arts based activity sessions as part of your recreation and leisure programming.

My goals for the training are that as a result of the programme I will be better able to:

## APPENDIX E

### PARTICIPANTS EVALUATION QUESTIONNAIRE

#### PURPOSE

To give you the opportunity to evaluate the Training Programme which has included off-site Training Days, on-site sessions and support for on-going creative groupwork. This questionnaire will help to evaluate the success of the training and we request your co-operation in its completion. Please tick the boxes of your choice and answer any questions as honestly as you can. Many thanks.

1) Do you think the Training Programme was;

Too short? ☐ About right? ☐ Too long? ☐

2) We have covered the following skill areas with an emphasis on Music, Movement and Song Reminiscence and Resources and Groupwork and Leadership skills. We ask you to rate the areas you have found 'Very Helpful' through to 'Confusing' by giving each a score and placing that score in the appropriate box (Score 5 = Very useful, 4 = Helpful, 3 = No difference, 2 = Unhelpful, 1 = Confusing ).

a) Music Movement and Song ☐ b) Reminiscence and Resources ☐

c) Groupwork & Leadership skills ☐

3) What have been the benefits of this work for your residents and older people? Do you have any comments from residents and attenders about what they thought of the programme of sessions ? If so please list them here;

4) What have been the key benefits for you professionally?  
Please tick no more than 3 statements.

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- |  |   |                          |
|--|---|--------------------------|
| 1)Increased Confidence to run groups   | 2)Learnt new ways to organise more interesting activities for residents/clients | <input type="checkbox"/> |
| 3)Increased self worth   | 4)Improved Teamworking  | <input type="checkbox"/> |
|  | 5)More job satisfaction   | <input type="checkbox"/> |
| 6)Improved Creativity/More imaginative   | 7)Better session planning   |                          |
| 8)Better understanding of residents and clients needs/More able to respond effectively to them |   |                          |
| 9)Better understanding of groupwork  | 10)Better able to provide activities sessions for people with Dementia          |                          |
| 11)More expressive   | 12)Having time to build up good relationships with residents, clients and staff |                          |

Others (please write here);

5) What have been the key benefits for you personally? Please tick no more than 3 statements.

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- |  |                        |   |                          |
|--|------------------------|---|--------------------------|
| 1)More outgoing and confident                                | 2)More motivated       | 3)More self respect                             | <input type="checkbox"/> |
| 4)More patient   | 5)Sense of achievement | 6)Better problem solving                        | <input type="checkbox"/> |
| 7)Bringing pleasure to the lives of the people you work with |                        |   | <input type="checkbox"/> |
| 8)More able to draw people out of themselves                 |                        |   |                          |
| 9)Sense of joy/laughter and enjoyment                        |                        |   |                          |
| 10)Learning about residents past and background              |                        | 11)Working with staff from other establishments |                          |
| 12)More aware of own untapped and available talent           |                        |   |                          |

Others:

6) Has the knowledge and skills you have gained, increased your confidence in your work?  
Yes ☐ No ☐ Not sure ☐

7) Do you think the skills you have gained will improve the quality of Care Service Provision in your workplace?  
Yes ☐ No ☐ Not sure ☐

8) Has the Training increased the confidence and capacity of you the staff team to meet the needs of those within your care more imaginatively ?  
Yes ☐ No ☐ Not sure ☐

9) Has the Training increased the confidence and capacity of you the staff team to meet the needs of those within your care more effectively ?

Yes ☐ No ☐ Not sure ☐

10) Has the programme enhanced the participating resident / attender's sense of wellbeing within the home or day hospital ?

Yes ☐ No ☐ Not sure ☐

11) Has the programme at Garden View in particular helped support you in the future to be able to work with resident's / attenders who may be more mobile, more active and with a less severe form of dementia syndrome, once the Unit moves to a new site ?

Yes ☐ No ☐ Not sure ☐

12) What difficulties do you anticipate in implementing these ideas? Please tick 3 statements of your choice;

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- |                          |                            |                      |
|--------------------------|----------------------------|----------------------|
| 1)Session Planning       | 2)Comms. with Management   | 3)Space problems     |
| 4)Timing problems        | 5)Resourcing diffs.        | 6)No cassette player |
| 7)Not enough training    | 8)No reviewing time        | 9)Not enough tapes   |
| 10)Running sessions well | 11)Motivating participants | 12)Staffing problems |

Others; Please list here;

13) For staff at Garden View in particular. Have you noticed any changes in the life of the home outside of the sessions ? For example have you noticed any changes in behaviour of residents once sessions are over, or in the overall atmosphere within the home? Please list here:

14) Any administrative difficulties associated with the training programme? Please list here;

15) Lastly we invite you to make any comments which would help us improve the quality of the programme, which we could incorporate into any subsequent trainings; (Many thanks indeed).

Richard Coaten (May 2002). Many thanks for your help in completing this evaluation.

APPENDIX F

The Leeds Teaching Hospitals **NHS**

**Local Research Ethics Committee** NHS Trust

6th Floor, Wellcome Wing, The General Infirmary at Leeds,  
Great George Street, Leeds LS1 3EX. Telephone 0113 3926788

Mr R B Coaten  
46 East View  
Yeadon  
Leeds LS19 7AD

Enquiries to: Jacqueline Lower  
Direct Line: 0113 392 6788  
Our Ref: **CA01/108**  
Your Ref:  
Date: 21 August 2001

Dear Mr Coaten

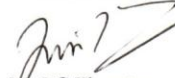
**Re: CA01/108 Working within the NHS: evaluating the effects of an arts based approach on older people with dementia and their care staff**

Thank you for submitting details of the above research study protocol for ethical review.

This study is suitable for consideration by chairman's action and I am able to give full approval for it to proceed.

This approval is subject to the conditions of approval set out below.

Yours sincerely



Mr J G Thornton  
Acting Chairman  
Research Ethics Committee  
Leeds Health Authority/United Leeds Teaching Hospitals

**Conditions of approval**

The Committee approves a project on the basis of the key information contained in the completed proforma which includes the Patient Information Sheet and Consent Form. It is the responsibility of the Investigators to ensure that the synopsis accurately reflects the protocol for the study. The Patient Information Sheet approved by the Committee must be used for the study. You must follow the protocol agreed and any changes to the protocol will require prior LREC approval. The project must be started within three years of the date of final approval.

You must inform the committee promptly of:

- changes to the protocol which are made to eliminate immediate hazards to the research subjects
- any changes that increase the risk to the subjects and/or significantly affect the conduct of the research
- all adverse drug reactions that are both serious and unexpected

Chairman Bill Kilgallon OBE Chief Executive David Johnson

The Leeds Teaching Hospitals Incorporating: Chapel Allerton Hospital Cookridge Hospital Leeds Chest Clinic  
Leeds Dental Institute Seacroft Hospital St James's University Hospital The General Infirmary at Leeds  
Wharfedale Hospital

WTA068